AHRQ Long COVID Care Network

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OCTOBER 12, 2024

UW Medicine

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  - If you have difficulty locating them, email LongCovidClinic@uw.edu

Or via the QR Code here!

UW Medicine

Long COVID:
Forging the Path Ahead

Tiffany Walker, MD

Keynote Address

October 12, 2024

2024
Long COVID RISE
Symposium

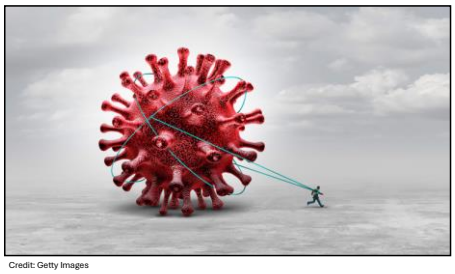
UW Medicine
DEPARTMENT OF REHABILITATION MEDICINE

Atlanta Long COVID
Collaborative

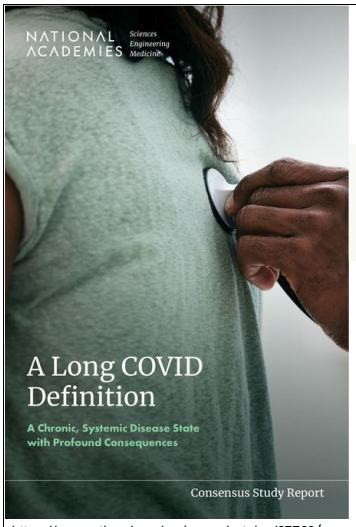
EMORY
UNIVERSITY
SCHOOL OF
MEDICINE

"In an age when medicine is based on evidence: What can be done for people who live at the edge of medical knowledge?"

-Meghan O'Rourke
NASEM Workshop: Toward a Common Research Agenda in Infection-Associated Chronic Illnesses



Credit: Getty Images



2024 NASEM Long COVID Definition

Long COVID (LC) is an infection-associated chronic condition (IACC) that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

https://nap.nationalacademies.org/catalog/27768/

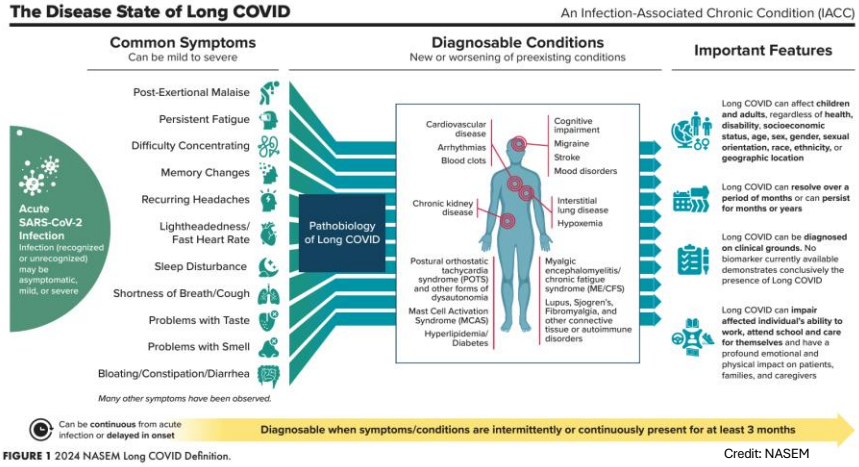


FIGURE 1 2024 NASEM Long COVID Definition.

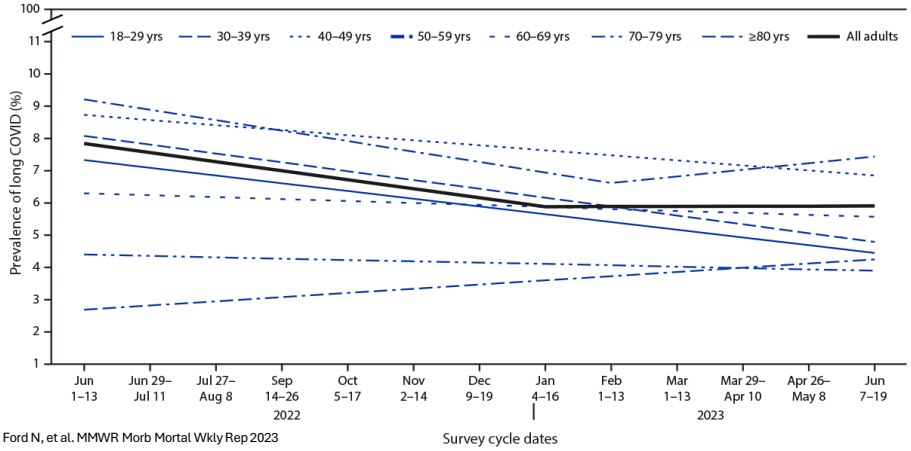
Credit: NASEM

https://nap.nationalacademies.org/catalog/27768/
Thaweethai T, et al. JAMA. 2023

Credit: DC Health

Khullar, D., et al. JGIM. 2023
Huang C, et al. Lancet 2021
Cohen J., et al. Int J Equity Health. 2023

Trend lines for the prevalence of self-reported long COVID among all adults,* by age group — Household Pulse Survey, United States, June 1–June 13, 2022 to June 7–June 19, 2023†



Ford N, et al. MMWR Morb Mortal Wkly Rep 2023

Morbidity and Mortality Weekly Report (*MMWR*)

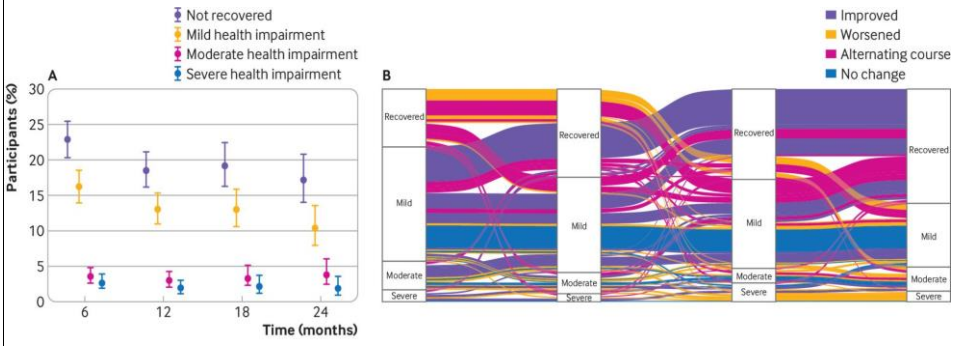
Search

Long COVID and Significant Activity Limitation Among Adults, by Age — United States, June 1–13, 2022, to June 7–19, 2023

Weekly / August 11, 2023 / 72(32):866–870

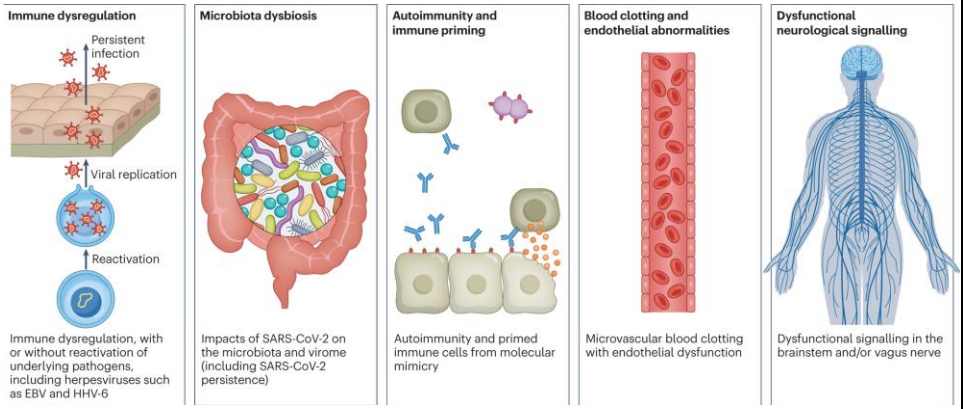
Ford N, et al. MMWR Morb Mortal Wkly Rep 2023

Long COVID prognosis



Ballouz T. et al. BMJ. 2023

Proposed pathobiological mechanisms



Davis, H.E., et al. Nat Rev Microbiol.2023

Diagnostic & management guidance

aapm&r

Long COVID/PASC

Published Guidance

- Mental Health Guidance Statement
- Neurological Symptoms Guidance Statement
- Autonomic Dysfunction Guidance Statement
- Pediatrics Guidance Statement
- Cardiovascular Complications Guidance Statement
- Cognitive Symptoms Guidance Statement
- Breathing Discomfort Guidance Statement
- Fatigue Guidance Statement

https://www.aapmr.org/advocacy/current-priorities/long-covid-pasc/pasc-guidance

No FDA-approved Long COVID treatments¥

Symptom/Syndrome	Pharmacologic	Non-pharmacologic
Long COVID	Antihistamines (cetirizine/loratadine and famotidine)	Validation, education, accommodations
Fatigue/PEM	low-dose naltrexone (LDN), SSRI, low dose aripiprazole, amantadine, Strattera	PEM-monitored physical rehabilitation, 4P's (planning, pacing, prioritizing, positioning)
Brain fog	LDN, guanfacine, Strattera	Neurocognitive testing/rehabilitation
Shortness of breath/cough	Inhaled steroids, fluticasone/salmeterol, tessalon perles	Physical rehabilitation
Musculoskeletal pain	LDN, duloxetine, meloxicam, TCAs	Physical rehabilitation
Neuropathic pain	Gabapentin	
Headache	Antihistamines, gabapentin, amitriptyline	
Dysautonomia	Beta blockers, midodrine, fludrocortisone, antihistamines, guanfacine	Fluids, salt, abdominal binders, recumbent physical therapy
Depression/Anxiety	SSRIs	Individual and group session therapy

¥ Repurposed drugs are based on observational data or small clinical trials in Long COVID or overlap infection-associated chronic conditions (IACCs)

Glynne P, et al. J Investig Med. 2022
Bonilla H, et al. Int Immunopharmacol. 2023
Sanal-Hayes NEM, et al. J Transl Med. 2023
Crosby, L.D., et al. J Transl Med. 2021
Harandi, A.A., et al. Sci Rep. 2024
Rus, C.P., et al. Sci Rep 2023
Fesharaki-Zadeh A, et al. Neuroimmunology Reports. 2023
Lunn MP, et al. Cochrane Database Syst Rev. 2014
Griesel M. et al. Cochrane Database Syst Rev. 2022
Ghadiri-Sani M, et al. BMJ Clin Evid. 2016
Vernino S, et al. Auton Neurosci. 2021

RECOVER
Researching COVID to Enhance Recovery

RECOVER Clinical Trials

1. RECOVER- VITAL
   - Study Details | RECOVER-VITAL: Platform Protocol to Measure the Effects of Antiviral Therapies on Long COVID Symptoms | Paxlovid
2. RECOVER- NEURO
   - Study Details | RECOVER-AUTO: Platform Protocol to Measure the Effects of Therapies on Long COVID Neurocognitive Dysfunction | Neurocognitive rehabilitation
3. RECOVER- AUTO
   - Study Details | RECOVER-AUTO: Platform Protocol to Measure the Effects of Therapies on Long COVID Autonomic Dysfunction | Ivabradine & IVIG
4. RECOVER- SLEEP
   - Study Details | RECOVER-SLEEP: Platform Protocol to Measure the Effects of Therapies on Long COVID Symptoms | Modafinil & Solriamfetol
5. RECOVER- ENERGIZE
   - Study Details | RECOVER-ENERGIZE: Platform Protocol to Measure the Effects of Cardiopulmonary Rehabilitation on Long COVID Symptoms | Cardiopulmonary rehabilitation

https://trials.recovercovid.org/

Path forward: Research infrastructure

https://www.help.senate.gov/hearings/addressing-long-covid-advancing-research-and-improving-patient-care

Clinical trials

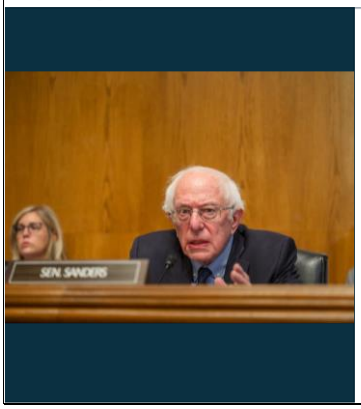
- Define phenotypes
- Develop diagnostic and surrogate biomarkers
- Equitable access to clinical trials
- Increase scale and diversity of clinical trials
- Coordinate data sharing and linkage
- Establish an NIH center for IACCs

Clinical Care

- Expand Long COVID care networks
- Establish clinical guidelines for treatment
- Identify bias in diagnosis and treatment
- Support programs for underserved communities

04.09.2024

NEWS: Chairman Bernie Sanders Releases Long COVID Moonshot Legislative Proposal



Proposal

- $1 billion in mandatory funding per year for 10 years
- Create a centralized coordinating entity
- Require NIH to establish a new grant process for clinical trials
- Establish an NIH research advisory board
- Require NIH to establish a Long COVID database
- Require federal entities to provide continued education and support

Themes

- Urgent timelines
- Patient partnerships
- Inclusion of vulnerable populations
- Develop Long COVID endpoints
- Identify biomarkers
- Small exploratory clinical trials and large adaptive platform trials
- Repurposed medications and drug development in collaboration with industry
- Build on existing infrastructure
- Agent submission portal

NIH National Institute of Allergy and Infectious Diseases

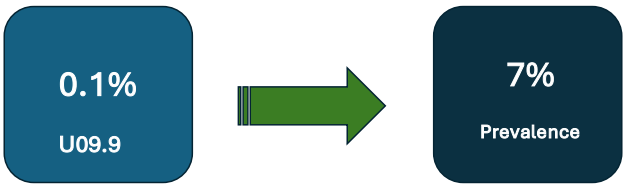
FNIH

https://fnih.org/our-programs/accelerating-covid-19-therapeutic-interventions-vaccines-activ/recover-tlc-will-advance-long-covid-research/

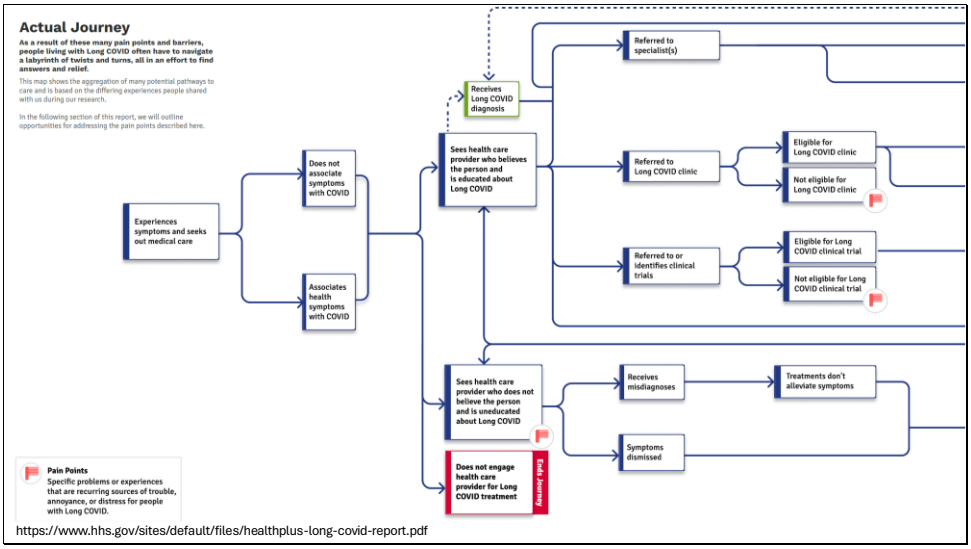
Long COVID care networks

Primary care screening

ICD-10 U09.9: Post-COVID Condition

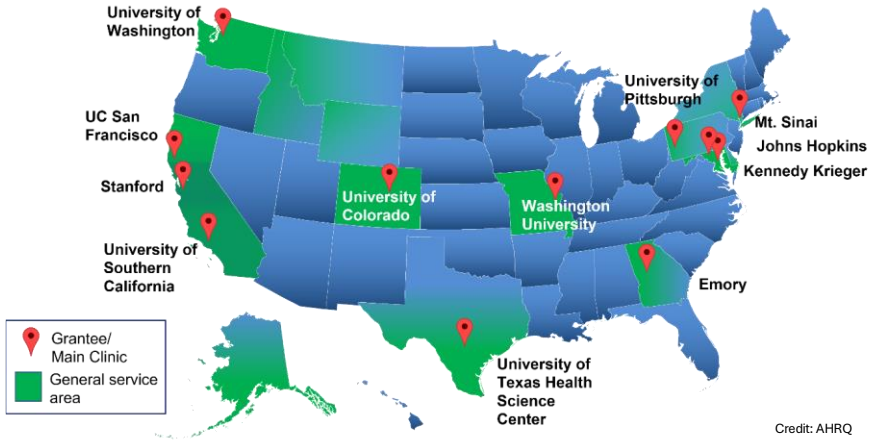


Unpublished data from Atlanta Long COVID Collaborative
Ford N, et al. MMWR Morb Mortal Wkly Rep 2023



https://www.hhs.gov/sites/default/files/healthplus-long-covid-report.pdf

AHRQ Long COVID care network grantees

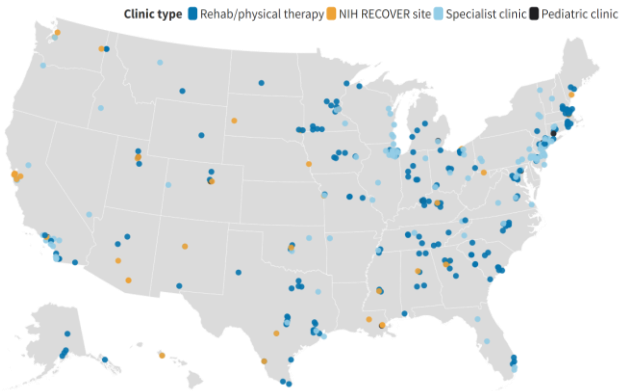


Credit: AHRQ

ATL Long COVID Collaborative
CENTER OF EXCELLENCE

GOALS	Equitable Long COVID Care Access	Person-Centered Care Model	Multidisciplinary & Behavioral Health
APPROACH	• Increase clinic staff and service hours • Increase telemedicine and e-consult options • Increase social services and resources • Community outreach • Provider education	• Increase care coordination staff & services • Patient advisory committee • Engage community organizations • Patient-centered program evaluation	• Behavioral health individual and group sessions • Increase subspecialty service lines offered • Multidisciplinary case conferences

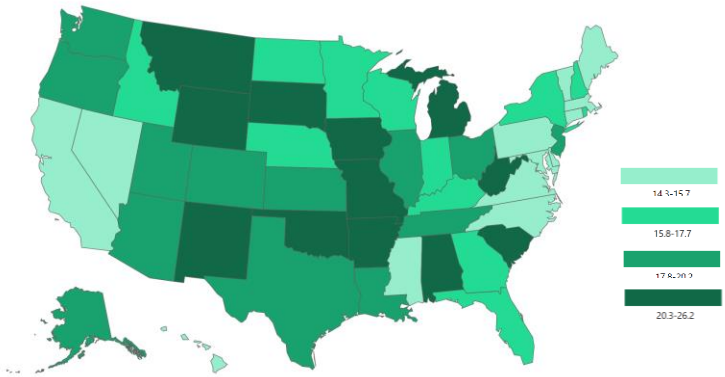
Long COVID care sites



https://www.sciencenews.org/article/long-covid-clinics-map-locations-prevalence
https://www.longhauler-advocacy.org/

Credit: Science News

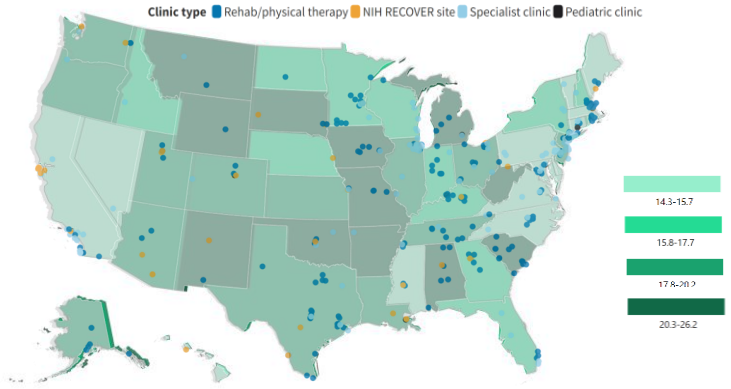
Ever experienced Long COVID, percentage of adults



https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm

Credit: CDC

Ever experienced Long COVID, percentage of adults



https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm

Credit: Science News & CDC

Path forward: LC network expansion & Decentralizating LC care

Long COVID network expansion

- Map Long COVID care providers
- Link networks
- Expand access & ensure geographical coverage
- Establish a common mission with guiding principles
- Define evidence-based practice guidelines

Credit: Getty Images

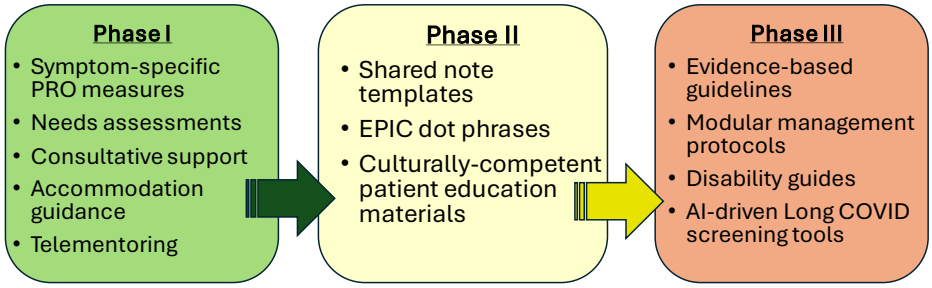
Decentralizing Long COVID care

- Build capacity at primary care level
- Identify & address common barriers
- Prioritize FQHCs and healthcare systems supporting vulnerable populations

Barriers to primary Long COVID care

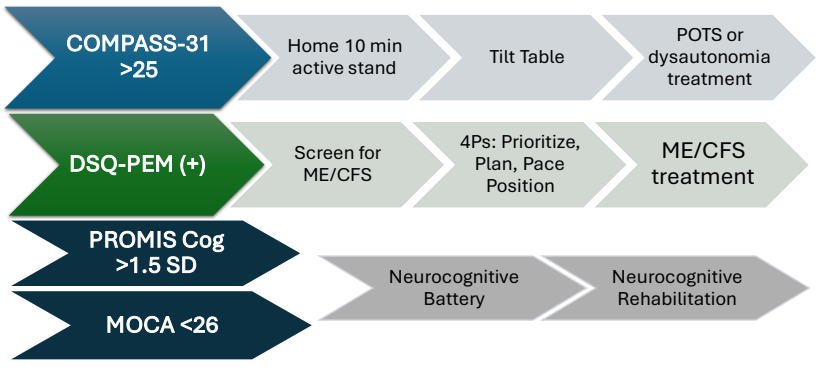
- Awareness & education
- Time constraints
- Staffing limitations
- Accommodations
- Disability
- Leadership investment

Long COVID: Primary care partnership opportunities



https://www.aapmr.org/advocacy/current-priorities/long-covid-pasc/pasc-guidance
Pfaff ER, et al. Lancet Digit Health. 2022

Patient reported outcome (PRO) measures



Sletten DM, et al. Mayo Clin Proc. 2012
Cotler J, et al. Diagnostics. 2018
Becker H, et al. Int J MS Care. 2014
Freitas S, et al. Alzheimer Dis Assoc Disord. 2013

Accommodation resources

- Job Accommodation Network (JAN): Practical Guidance for Medical Professionals
- JAN: Accommodation and Compliance: Long COVID Key Accommodations - Includes common workplace accommodations organized by long COVID symptom/limitation.
- HHS: health+ Long COVID Human-Centered Design Report - Framework and recommendations, map of the "ideal" versus "actual" treatment journey and patient-identified pain points.

Telementoring resources

Building Clinical Capacity Through the Long COVID and Fatiguing Illness Recovery Program

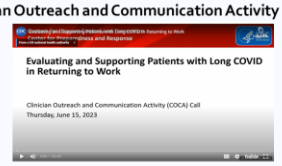
FAMILY HEALTH CENTERS OF SAN DIEGO

HEALTH SCIENCES ECHO

University of Colorado Anschutz Medical Campus | UW Medicine

Public Program | iECHO

Clinician Outreach and Communication Activity (COCA)



Evaluating and Supporting Patients with Long COVID in Returning to Work (cdc.gov)

Global Long Covid ECHO Webinar Series: Exploring Clinical Practice and Research

SILC

HEALTH SCIENCES ECHO

WHO Collaborating Centre for Digital Learning in Health Emergencies

Global Long Covid ECHO Webinar Series: Exploring Clinical Practice and Research | iECHO

Long-COVID ECHO

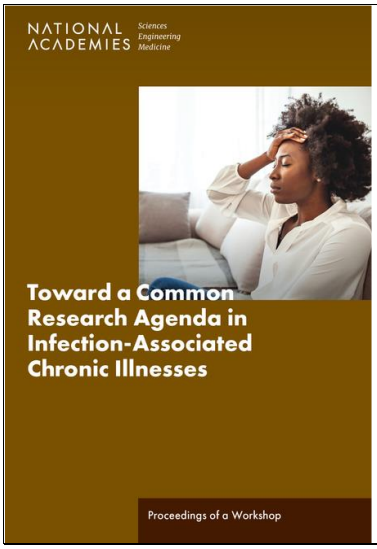
ASU Arizona State University

Long-COVID ECHO | College of Health Solutions (asu.edu)

Long COVID Clinical Podcast

UW Medicine | The Ohio State University | IHOCRC

Infection Associated Chronic Conditions (IACC)



Themes

- Substantial overlap in pathophysiology among IACCs
- Need for diagnostic testing at different stages of disease
- Identify therapeutic targets
- Prevention of IACCs
- Collaboration and coordination across stakeholders and practitioners to advance research and improve care

https://www.nationalacademies.org/our-work/toward-a-common-research-agenda-in-infection-associated-chronic-illnesses-a-workshop-to-examine-common-overlapping-clinical-and-biological-factors

AAIACC

Advancing education, advocating for research, enhancing clinical care, and promoting equity in the management of infection-associated chronic conditions.

EQUITY > EDUCATION > RESEARCH > RESOURCES > PROFESSIONAL DEVELOPMENT >

Anita Chopra, MD | Tiffany Walker, MD | Andrew Schamess, MD | Hector Bonilla, MD | Lisa McCorkell, MPP

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- https://www.hhs.gov/sites/default/files/healthplus-long-covid-report.pdf
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- https://askjan.org/disabilities/Long-COVID.cfm
- https://www.hhs.gov/ash/osm/innovationx/human-centered-design/longcovid/index.html
- Building Clinical Capacity through Long COVID and Fatiguing Illnesses Recovery Program: https://iecho.org/public/program/PRGM16990442188791ERCAXHJ8Y
- https://emergency.cdc.gov/coca/calls/
- Global Long COVID ECHO: https://iecho.org/public/program/PRGM16782067036655XBA2JB5VDC
- Long COVID ECHO: https://chs.asu.edu/project-echo/join/long-covid-echo
- AAIACC: http://www.aaiacc.org/index.php

Q & A

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:

Context for Long COVID and other Post-Acute Infection Syndromes

2024 Long COVID Recovery, Insights, Support, and Education (RISE) Symposium

UW Medicine, Department of Rehabilitative Medicine

October 18, 2024

Elizabeth R. Unger PhD, MD
Chief, Chronic Viral Diseases Branch
Division of High-Consequence Pathogens and Pathology
National Center for Emerging and Zoonotic Infectious Diseases

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Disclaimers

- **No conflict of interest to declare**
- **The findings and conclusions in this talk are mine and do not necessarily represent the official position of the US Centers for Disease Control and Prevention (CDC)**

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Outline

- Introduction to ME/CFS
- Infection-Associated Chronic Conditions and Illnesses (IACI) – Considerations
- Complexity of IACI - Implications for how ME/CFS relates to Long COVID
- Learning from ME/CFS
- Closing Comments

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Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Introduction

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Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

- **A serious long-term multi-system illness**
- **Post-exertional malaise (PEM), the worsening of symptoms after previously tolerated physical or mental activity, is hallmark**
  - Activities limited by fatigue and associated symptoms
- **Can persist for years, leading to poor quality of life and sometimes total disability**
  - ~1 in 4 patients with ME/CFS bed- or house-bound for prolong time
- **Patients often not believed by healthcare providers**
  - Lack of known pathogenesis and diagnostic test contribute to stigma

http://iom.nationalacademies.org/reports/2015/me-cfs.aspx

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Institute of Medicine 2015 Diagnostic Criteria

1. Substantial reduction or **impairment in the ability to engage in pre-illness levels of 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 **AND**
2. **Post-exertional malaise AND**
3. **Unrefreshing sleep**

PLUS at least one of the two following manifestations (chronic, severe):

1. Cognitive impairment OR
2. Orthostatic intolerance

http://iom.nationalacademies.org/reports/2015/me-cfs.aspx

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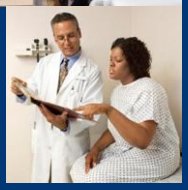
Epidemiology of ME/CFS



- **As many as 3.3 million Americans have ME/CFS**
  - Many have not been diagnosed
  - Most have been ill longer than 5 years, but only about 50% continue to seek medical care
- **Anyone can get ME/CFS**
  - Highest prevalence in 40- to 50-year-olds, but children and adolescents are affected
  - In adults, 3-4 times more common in women than men
  - Suggestion of higher prevalence in minority and socioeconomically disadvantaged populations

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Healthcare for people with ME/CFS

- **Diagnosis relies on symptom profile and clinical history**
  - 2015 IOM Diagnostic Criteria
  - Objective biologic abnormalities lack diagnostic sensitivity and specificity
  - **Post-exertional malaise** is a key feature, requires probing
- **Careful medical history, physical examination and testing are required**
  - Identify treatable illnesses that could cause symptoms
- **No approved drugs for ME/CFS**
  - Symptomatic management
  - Empathetic supportive care can reduce suffering

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Infection-Associated Chronic Conditions and Illnesses

Considerations

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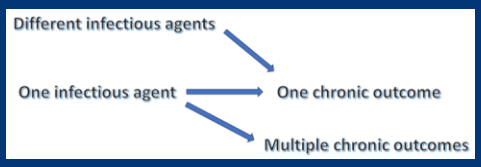
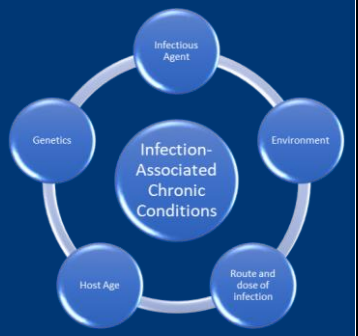
2004 Report from National Academies of Sciences, Engineering and Medicine (NASEM, formerly IOM)

- **Infectious etiology of chronic diseases: linking infectious agents and chronic diseases**
  - Emphasized breadth and complexity of link between infections and chronic diseases
  - Noted wide range of infectious pathogens (parasites, bacteria, viruses, prions) involved
  - Recognized challenges in making the link to infection





https://nap.nationalacademies.org/read/11026

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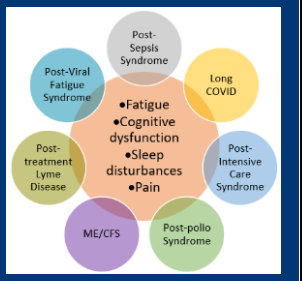
Unexplained post-acute infection syndromes (PAIS)

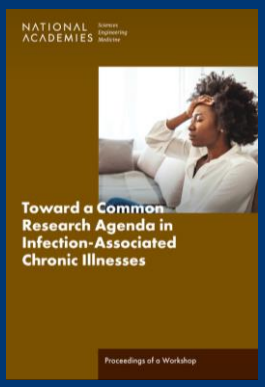
- **Recognized as "failure to recover" from wide variety of infections**
  - Infection not always documented or known
- **Core symptoms**
  - Exertional intolerance (post-exertional malaise)
  - Activity limitations due to disproportionate fatigue
  - Neurocognitive problems ("brain fog")
  - Sleep problems
  - Recurrent flu-like symptoms
- **Wide variety of additional symptoms may be present**
  - Some "trigger" specific
  - Results in heterogenous clinical picture
  - Chronic complex illness requiring symptom management



Choutka J, Jansari V, Hornig M, Iwasaki A. Nat Med (2022) 28:911-913

2024 NASEM Report – Toward a Common Research Agenda in Infection-Associated Chronic Illnesses

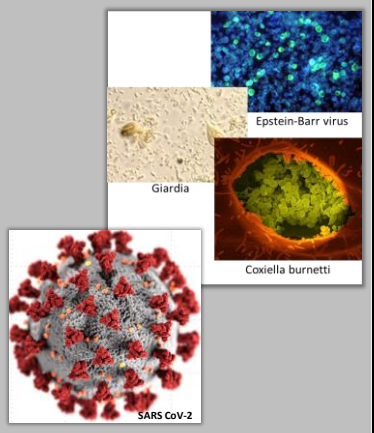
- **Focused on unexplained syndromic illnesses that follow acute infection**
  - Decided against PAIS terminology because of uncertainty that triggering infection cleared
- **Talks were largely infection-specific**
  - Syndrome following each infection studied individually
  - No specific diagnostic tests and treatment
  - Significant symptom overlap
- **Importance of patient-centered view of these illnesses emphasized**



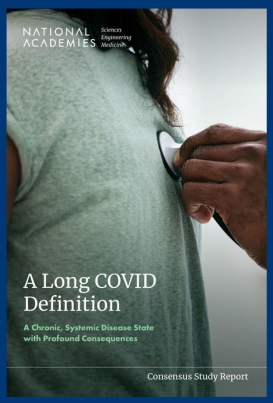
https://nap.nationalacademies.org/catalog/27462/toward-a-common-research-agenda-in-infection-associated-chronic-illnesses

ME/CFS – An Infection-Associated Chronic Condition

- **Infection is a recognized risk factor**
  - No one pathogen is implicated
  - Long COVID brought attention to this
    - ME/CFS recognized as part of Long COVID
- **Non-infectious risk factors**
  - Stressors
    - Physical trauma, surgery, or significant stress
    - Allostatic load
  - Genetics
  - Environment (toxins)



Long COVID - An Infection-Associated Chronic Condition



NASEM 2024 Long COVID Definition

- **Long COVID is an infection-associated chronic condition that occurs after SARS CoV-2 infection**
  - Present at least 3 months as continuous, relapsing and remitting or progressive disease state
  - Affects one or more organ systems
  - Can range from mild to severe
  - More than 200 symptoms and conditions possible
  - Can affect children and adults
  - Can have profound emotional and physical impact

https://nap.nationalacademies.org/catalog/27768/a-long-covid-definition-a-chronic-systemic-disease-state-with

Complexity of Infection-Associated Chronic Illnesses (IACIs)

Implications for how ME/CFS relates to Long COVID

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Long COVID presentations – proposed grouping of NASEM listed diagnosable conditions

Manifestations of Long COVID		
Group 1 - Organ Damage	Group 2 - Autoimmune Conditions	Group 3 - Unexplained Syndromes
interstitial lung disease and hypoxemia	systemic lupus erythematosus	ME/CFS
cardiovascular disease and arrhythmias	rheumatoid arthritis	postural orthostatic tachycardia syndrome
chronic kidney disease	Sjögren's syndrome	dysautonomia
stroke	connective tissue diseases	mast cell activation syndrome
blood clots		fibromyalgia
hyperlipidemia		migraine

Mood disorders and anxiety are diagnosable conditions common in persons experiencing chronic illness. Cognitive impairment may be attributable to conditions within any of the three groups

- **Conditions in Group 1 and 2 have diagnostic abnormalities in clinical tests and established therapies that are not altered by linkage to COVID-19**
  - Group 2 requires combination of biomarkers and clinical history
- **Group 3 conditions are challenging, complex, overlapping conditions.**
  - Symptom-based diagnosis and management, poorly recognized, correspond to PAIS

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Heterogeneity of Long COVID

- **Patients do not always fall neatly into one group**
- **Best considered a group of infection-associated conditions**
- **Group 3 conditions – unexplained syndromic conditions are most challenging for patients and clinicians**
  - Area where lessons learned from caring for patients with ME/CFS most valuable

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Learning from ME/CFS

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CDC's ME/CFS Program – resources for Long COVID

- **Standardized measures of symptoms**
- **Toolkits for patients and healthcare providers**
- **Clinical education**
- **Approach to management**
- **Recognition of PEM**
- **Partnerships with patients**
- **Pediatric considerations**
  - Information for teachers, schools

https://www.cdc.gov/me-cfs/about/index.html
https://www.cdc.gov/me-cfs/toolkit/index.html

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ME/CFS experience anticipates need for clinical care of patients with Long COVID

- **Access to healthcare providers with required knowledge and expertise remains major concern of patients with ME/CFS**
  - Tertiary care centers for ME/CFS have long waitlists
  - Need for primary care clinicians to be educated and empowered to care for these patients
- **Impetus for Long COVID and Fatiguing Illness Recovery Program**
  - Integrated approach to IACIs in primary care

https://iecho.org/program/PRGM16990442188791ERCAXHJ8Y/details

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Long COVID and Fatiguing Illness Recovery Program (LC&FIRP)

FAMILY HEALTH CENTERS OF SAN DIEGO

HEALTH SCIENCES ECHO

UW Medicine

University of Colorado Anschutz Medical Campus

- **Evaluate multi-disciplinary team approach to improve quality of life and support recovery of people living with Long COVID, ME/CFS and related IACIs**
  - Improve care for patients with these conditions
  - Develop confidence in managing these conditions among safety-net clinic primary care providers
  - Disseminate advances and promising management practices
  - Multi-disciplinary tele-mentoring at heart of the program

BMC Trials 24:524, 2023

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ME/CFS clinical experience assisted LC&FIRP

- **Lived experience experts in every session, many of whom had ME/CFS**
  - Shared clinical experiences faced by Long COVID patients
  - Established patient-centered dialogue
- **Clinical consultants included ME/CFS physicians**
  - Emphasized importance of avoiding post-exertional malaise
  - Shared information on diagnosis and symptom management
    - https://mecfscliniciancoalition.org/
  - Suggested NASA Lean Test to diagnose postural orthostatic hypotension (POTS) or other forms of orthostatic intolerance

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Closing Comments

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Long COVID advances need to include ME/CFS

- **Shared symptoms and approach to clinical management argue for inclusion of IACIs in one clinical setting**
  - Ideally multi-disciplinary
- **Clinical guidelines are applicable to both conditions**
  - Examples - AAPM&R 'PASC' Collaborative Compendium and ME/CFS Clinician Coalition
- **Research and clinical trials need to account for heterogeneity**
- **Advantages to using IACIs with different known or unknown infectious triggers as comparison groups**

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Remember

- **Facts don't convey the full picture of these illnesses**
  - Listen to your patients and their caregivers
- **Empathetic supportive care can reduce suffering**
- **Reduce barriers to care by making accommodations in clinic**
  - Provide space for lying down and option for quiet, dimmed lighting waiting area
    - Postural hypotension, light and noise sensitivities are common
  - Be sensitive to patients needs when walking them to exam room
    - Rapid walking pace can leave patient feel abandoned

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Thank you

Chronic Viral Diseases Branch
Jeanne Bertolli
Dane Benedict
Dana Brimmer
Yang Chen
Liz Fall
Nanda Issa
Niyai Johnson
Maung Khin
Sally Lin
Troy Querec
Mangalathu Rajeevan
Quan Vu
Stephanie Weaver

LC&FIRP
Job Godino
Christian Ramers
Jane Samaniego
John Scott
Bruce Struminger
Doug Taren

Study Participants and Caregivers

https://www.cdc.gov/me-cfs/about/index.html

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"May 12 is International ME/CFS Awareness Day! We stand together and wear blue to support people with ME/CFS, their caregivers, friends, and family!"

THE OHIO STATE UNIVERSITY
WEXNER MEDICAL CENTER

Managing Cognitive Symptoms and Small Fiber Neuropathy in Long COVID

Andrew Schamess, MD

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Patient description of cognitive symptoms

Tara Gidwani – used with permission

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nature › nature medicine › review articles › article

Review Article | Published: 09 August 2024

Long COVID science, research and policy

Ziyad Al-Aly, Hannah Davis, Lisa McCorkell, Letícia Soares, Sarah Wulf-Hanson, Akiko Iwasaki & Eric J. Topol

Nature Medicine **30**, 2148–2164 (2024) | Cite this article

60k Accesses | **2781** Altmetric | Metrics

"Due to near-total absence of evidence from randomized clinical trials to guide treatment decisions, approaches for the assessment and treatment of respiratory sequelae, cardiovascular complications, fatigue, cognitive symptoms, autonomic dysfunction (including POTS) and neuropsychiatric impairment in adults and children are based on evidence of treating similar symptomatology from other conditions."

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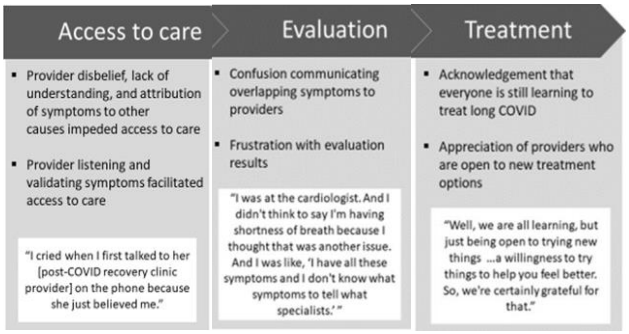
Healthcare Experiences



McAlearny, A. et al. (2023). Navigating Chronic Consequences of COVID-19:A Qualitative Study of the Experiences of Patients with Long COVID.2023 National Cancer Institute (NCI) Serological Sciences Network (SeroNet) Investigators Meeting, Bethesda, MD

70

Communication: sometimes better than pills

Diagnosis

- Validation is therapeutic for many patients
- Diagnosis allows patients to communicate with others (workplace, family, friends)
- Diagnosis permits chronic disease education and self-management

Prognosis

- Not bad for patients with duration < 12 months.
- Reason for optimism for recently infected.
- Allows planning for possible short-term or long-term disability, and necessary accommodations.

BRAIN FOG

Word-finding difficulty, speech dysfluency

Recollection – names, people, places

Trouble maintaining attention (i.e. losing the thread of a conversation midway)

Confusion in unfamiliar places / situations

Difficulty learning new information

Difficulty performing multi-step tasks (following a recipe, driving, job-related workflows)

Differential diagnosis / workup

- Attention deficit disorder – history, neuropsychological testing
- Post-concussive syndrome (h/o head injury)
- Dementia (older age, family history, more severe deficits)
- CNS lesion (focal deficits, new onset headaches, h/o primary cancer) – brain imaging
- Multiple sclerosis – h/o optic neuritis, transient focal deficits
- Medication side effects

FATIGUE

- Mental exhaustion
- Excessive desire to rest or sleep during the day
- Lack of energy/motivation to engage activities
- Fatigue may be
  - Constant (present from waking and continuing through the day)
  - Intermittent ("good days and bad days")
  - Progressive (i.e. utterly exhausted at the end of a workday)

Differential diagnosis / workup

- Sleep disorder – consider sleep study if history suggestive
- Anemia - lab
- Endocrine: hypothyroidism, hypoadrenalism, hypoandrogenism, menopause – lab screen
- Cardiomyopathy – consider echo
- Medication side effects

SLEEP DISORDER SYNDROMES OF POST-ACUTE SEQUELAE OF SARS-COV-2

47 patients referred to dedicated Post-COVID Sleep Clinic at Beth Israel Deaconess

Categories of sleep disturbances fell into five predominant sleep disorders:

- OSA 35.71 %
- Insomnia 28.57 %
- Primary hypersomnia 21.42 %
- REM behavior disorder (RBD) 11.9 %
- New onset circadian phase delay or circadian disturbances 4.76 %

Coelho FMS, Czuma R, Ticotsky A, Maley J, Mullington JM, Thomas RJ. *Sleep Med.* 2024;123:37-41.

POST-EXERTIONAL MALAISE (PEM)

Physical or mental exhaustion provoked by exertion

Patients often describe "crashing" a few hours or days after activity that they would have tolerated easily prior to Long COVID onset.

Most often associated with physical activity but can be caused by demanding cognitive tasks.

Often accompanies dysautonomia

Differential diagnosis / workup

- Angina – risk factors, symptom description (chest pain or dyspnea occurring consistently at a given level of exercise) – stress testing
- Coronary microvascular disease – positive stress test, normal coronary angiogram – may need coronary flow reserve testing
- Myasthenia gravis – ocular symptoms, dysarthria, dysphagia, proximal limb weakness – AChR and MuSK autoantibodies, EMG, Neurology referral

MOOD SYMPTOMS

- Unprecipitated anxiety – no trigger or situational context – probably due to sympathetic nervous system overactivity seen in Long COVID
- Adjustment disorder – depression and/or anxiety related to disease state and impact on work, financial stability, family responsibilities and quality of life
- Post-traumatic stress disorder
- Generalized anxiety disorder
- Major depressive disorder

First line: rest and pacing

Limited energy: you can use it to work, or you can use it to heal.	Ideally: one month off from work to for rest and rehabilitation. After that, stepwise return.	Modify based on what's feasible (sick time, company policies, financial stresses).
Owning your condition and asking for help. You have a serious illness and it's going to take time to recover.	Very successful approach in many patients.	Not for everyone (i.e. already disabled, retired, unable to take time off)

THE RELEVANCE OF PACING STRATEGIES IN MANAGING SYMPTOMS OF POST-COVID-19 SYNDROME

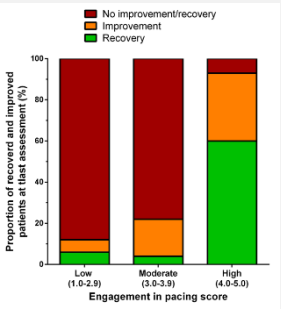
Retrospective case series based on medical record review

86 patients with Long COVID

Pacing strategies were systematically proposed for all patients. Adherence was assessed by the Engagement in Pacing Subscale (EPS)

Outcomes included Long COVID symptoms, fatigue features, perceived health status and employment activity.

Patients with higher EPS scores experienced significantly higher recovery and improvement rates (60–33.3% respectively) than those with low (5.5–5.5% respectively), or moderate (4.3–17.4% respectively) scores.



Ghali A, Lacombe V, Ravaiau C, et al. J Transl Med. 2023;21(1):375.

OUTCOMES OF OUTPATIENT GROUP COGNITIVE REHABILITATION IN LONG COVID PATIENTS

Modules of Intervention in a 3-Week-Group-Treatment Programme (10 Days of Treatment)			
Assessment	**Psychoeducation and Information**	**Exercise and Behavioural Activation**	**Compensation**
Neurological-psychiatric: incl. Schellongtest, blood parameters	Medical consultation	Day clinic schedule to regulate daytime structure	Fatigue management
Neuropsychological: attention, memory, executive functioning, mood, fatigue	Bio-psycho-social model of illness and recovery	Cognitive training	Compensatory strategies for cognitive deficits (e.g., external memory aids)
Physiotherapeutic: strength and endurance, vital capacity, oximetry, 6-minute walking-test	Pacing and energy management sleep hygiene	Communication and text processing	Mindfulness and acceptance Qigong
	Nutritional counseling	Training of fitness and strength	
	Social security counseling, incl. planning of occupational reintegration	"Homework" on individual projects	Resource activation

Key Aspects implemented Across Modules:

- **Recognition** of PCS as a physical illness while keeping the therapeutic focus on modifiable factors
- **Exchange** of experience in a closed group of 3-4 participants
- **Practice pacing** by allowing for individualized breaks and alternating physical and mental demands between sessions
- **Transfer** to the home and work environment facilitated by a day-clinic setting and therapy-free days

Prospective trial, 33 subjects

10 treatment days within 3 weeks, carried out in a fixed group of 3–4 patients.

In their qualitative evaluations, patients rated the program as helpful.

There was a significant reduction of depressive symptoms (p=.001), higher self-efficacy (p <.001) and social role participation (p <.001,) and marginally significant reductions in general psychological or physical distress and intensity of complaints.

Hasting AS, Herzig S, Obrig H, Schroeter ML, Villringer A, Thöne-Otto AIT. The Leipzig treatment program for interdisciplinary diagnosis and therapy of neurocognitive post-COVID symptoms: Experiences and preliminary results. Z Neuropsychol. 2023;34(2):71-83.

At least 10% improvement at 6 months compared with baseline	Amantadine − (n=61)	Amantadine + (n=14)
Fatigue	36%	75%
Sleep disturbance	36%	63%
Anxiety	33%	56%
Depression	32%	56%

PRELIMINARY DATA SUPPORTING THE USE OF AMANTADINE (MARCH 2023)

Database of 75 patients from OSUMC PASC Clinic with diagnosis by clinician of Post-COVID neurologic symptoms. PROMIS29 inventory completed at clinic enrollment and 6 months later. Unpublished data.

A randomized open-label clinical trial on the effect of Amantadine on post Covid 19 fatigue

Ali Amini Harandi[1,2*], Hossein Pakdaman[3], Aida Medghalchi[3], Negin Kimia[3], Alireza Kasemian[4], Fatemeh Siavoshi[3], Siavash Shirzadeh Barough[5], Akram Esfandiari[3], Mohammad Hossein Hosseini[3] & Seyed Ali Sobhanian[3]

Science Reports

(Nature Publication)

January 16, 2024

14(1):1343.

- Open label trial – amantadine versus no treatment
- 33 subjects in each group
- Matched by sex and history of hospitalization
- Average age 37; 63% female
- Amantadine dose 100 mg twice daily for two weeks

Visual Analogue Fatigue Scale	Before treatment	After treatment
Amantadine	7.90	3.37
Placebo	7.34	5.97
P-value	0.087	<0.001
Fatigue severity Scale		
Amantadine	53.10	28.40
Placebo	50.38	42.29
P-value	0.053	<0.001

GUANFACINE (AN ALPHA-2 ANTAGONIST) WITH N-ACETYL CYSTEINE IN LONG COVID

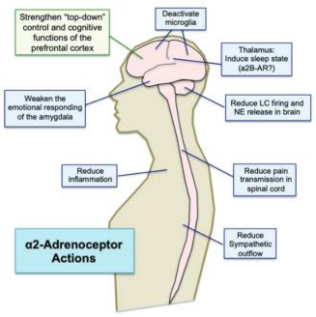
Case report: 12 patients were prescribed extended release guanfacine and NAC for Long COVID associated brain fog.

Dose: 1 mg PO at night for 1 month, increased to 2mg in month 2, if well-tolerated. NAC dose was 600 mg tab PO daily.

4 patients discontinued therapy, 2 for unspecified reasons and 2 due to hypotension and/or dizziness.

8 remain on medication with reported benefit. One patient reported having less difficulty with word-finding difficulties. Many reported improved working memory, concentration, and executive functions, e.g. multi-tasking. Two patients described feel- ing more like themselves again.

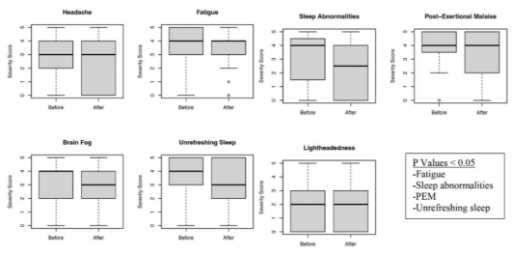
Clinical experience with the α2A-adrenoceptor agonist, guanfacine, and N-acetylcysteine for the treatment of cognitive deficits in "Long-COVID19." Fesharaki-Zadeh A, Lowe N, Arnsten AFT. Neuroimmunology Reports. 2023;3:100154.



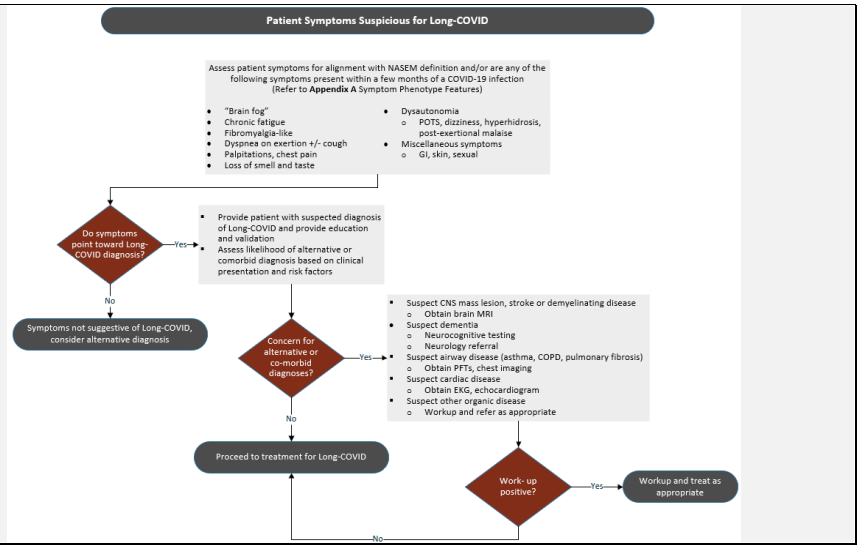
Arnsten AFT, Ishizawa Y, Xie Z. Scientific rationale for the use of α2A-adrenoceptor agonists in treating neuroinflammatory cognitive disorders. Mol Psychiatry. 2023;28(11):4540-4552.

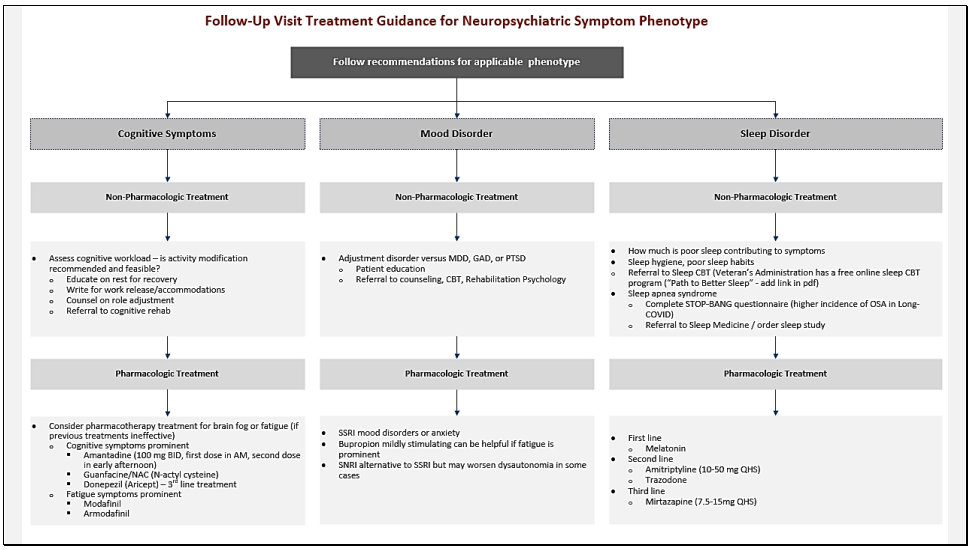
LOW DOSE NALTREXONE

- Retrospective case series based on chart review
- 59 patients with Long COVID (61-708 days)
- Median duration of treatment at time of chart review: 143 days
- Symptoms were ascertained using a 29-question survey completed by patients within 7 days before each clinic visit that captured common Long COVID symptoms and severity.



Bonilla H, Tian L, Marconi VC, et al. Low-dose naltrexone use for the management of post-acute sequelae of COVID-19. *Int Immunopharmacol*. 2023;124(Pt B):110966.





PAINFUL PARESTHESIAS

- Fibromyalgia-like syndrome characterized by constant or intermittent aching of muscles and/or joints.
- Typically, widespread or migratory.
- Degree of pain may vary with activity, sleep pattern or at random.
- Often accompanied by fatigue, poor sleep and brain fog.

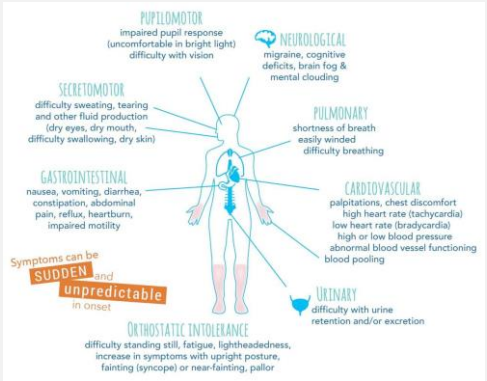
Differential diagnosis / workup

- Rheumatologic disease – history and exam, ESR, CRP, ANA
- Abnormal vibratory or monofilament testing suggest small fiber neuropathy – consider small fiber nerve biopsy
- Consider polyneuropathy workup – A1c, B1, B12, SPEP/UPEP, TSH, ANA, ESR, CRP
- If patient describes pain isolated to one muscle group (i.e. unilateral leg pain), consider MSK pain, radiculopathy, overuse syndrome

PAINFUL PARESTHESIAS – SYMPTOMATIC TREATMENT

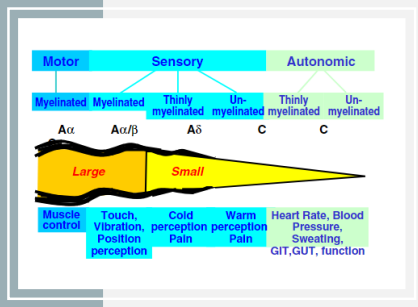
- Gabapentin or pregabalin
- TCA – amitriptyline or nortriptyline
- Low dose naltrexone
- SNRI – duloxetine or venlafaxine

DYSAUTONOMIA



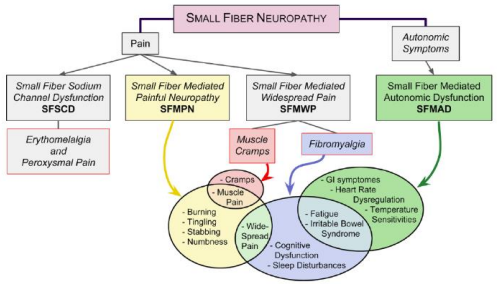
thedysautonomiaproject.org (used with permission)

A SIMPLIFIED VIEW OF THE PERIPHERAL NERVOUS SYSTEM



Vinik AI, Mehrabyan A. Diabetic neuropathies. Med Clin North Am. 2004;88(4):947-999, xi.

Small fiber neuropathy classification and associated symptoms (Levine 2018)



Levine TD. Small Fiber Neuropathy: Disease Classification Beyond Pain and Burning. *J Cent Nerv Syst Dis*. 2018;10:1179573518771703.

SMALL FIBER NEUROPATHY IN LONG COVID

Table 1: Studies to date that report on the prevalence of small fiber neuropathy in Long COVID using skin biopsy, QSART or specialized optic imaging for diagnosis

Study	Assessment technique	Population studied	Nr. of subjects	% with confirmed SFPN/AN
Abrams, RMC., *et al.* 2022. PMID: 34766365	skin biopsy	Subjects with new onset paresthesias 2+ months after COVID19	13	6 / 46%
Oaklander, AL., *et al.* 2022. PMID: 35232750	skin biopsy	Subjects with WHO-defined Long COVID referred for nerve biopsy for neuropathic symptoms	16	10 / 63%
Barros, A., *et al.* 2022 PMID: 34781021	corneal imaging	Subjects had COVID19 in past 9 months	23	21 / 91.3%
Hinduja, A., *et al.* 2021 PMID: 33551341	QSART	Subjects 3+ months after COVID19 complaining of fatigue or neurologic symptoms	50	13 / 26%
Varma-Doyle, A., *et al.* 2023. PMID: 36718227	QSART	Subjects with new onset or worsened autonomic symptoms after COVID19	6	6 / 100%

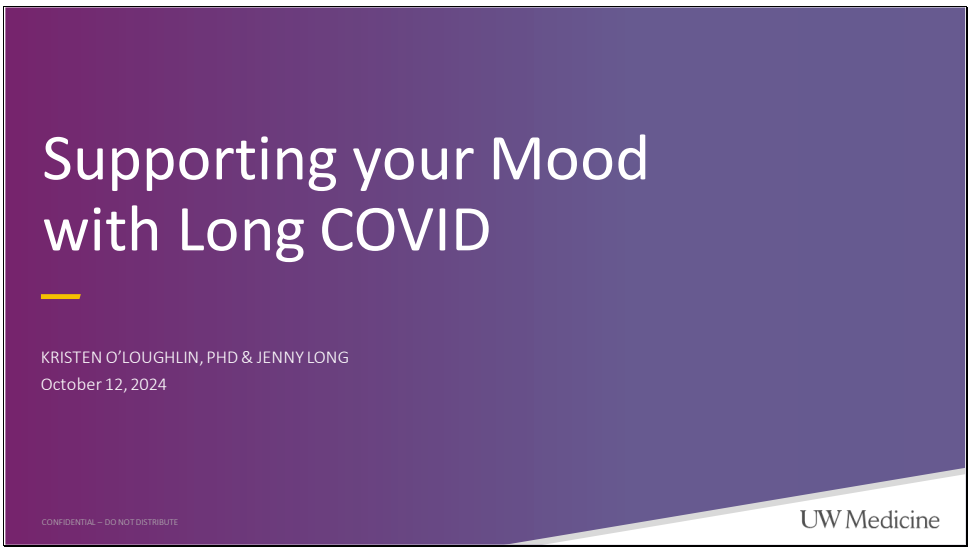
Peripheral Regulation of Central Brain-Derived Neurotrophic Factor (BDNF) Expression through the Vagus Nerve

- Adult hippocampal neurogenesis is necessary for memory formation, learning ability, mood regulation and stress response.
- BDNF is an essential regulator or adult hippocampal neurogenesis.
- Afferent signaling from the Vagus Nerve has a pivotal role in the regulation of the BDNF expression in the brain.

Amagase Y, Kambayashi R, Sugiyama A, Takei Y. Peripheral Regulation of Central Brain-Derived Neurotrophic Factor Expression through the Vagus Nerve. *Int J Mol Sci*. 2023;24(4). doi:10.3390/ijms24043543


Guest Speaker and Long COVID Clinic Panel + Q&A
DR. TIFFANY WALKER, MD (EMORY)
DR. ANDREW SCHAMESS, MD (OHIO STATE)
DR. JANNA FRIEDLY, MD, MPH (UNIVERSITY OF WASHINGTON)
DR. NIKKI GENTILE, MD, PHD (UNIVERSITY OF WASHINGTON)
UW Medicine


Immunity
JOSHUA ROMAN
UW Medicine


Supporting your Mood with Long COVID
KRISTEN O'LOUGHLIN, PHD & JENNY LONG
October 12, 2024
CONFIDENTIAL – DO NOT DISTRIBUTE
UW Medicine

The Long COVID Experience: Common Challenges

- Symptoms
  - Fatigue[1,2]
  - Shortness of Breath[1,2]
  - Brain Fog[3]
  - Depression/Anxiety[4]
- Psychological Impact
  - Feeling trapped in a cycle of exhaustion[5]
  - Feeling disconnected from their previous life or activities[5]
  - Loss of identity or life purpose[5]
  - Fear of the future or unknown[5,6]

The Story of Long COVID

- Many patients' share stories of their Long COVID experience which center around loss—of energy, health, normalcy.
- These stories are centered around the problem.

I am too tired to do anything.

I am no longer myself.

Shifting the Narrative

- Externalize Long COVID from your identity:
  - Long COVID is a *part* of your experience, but it *doesn't define* who you are
- Developing an alternative story:
  - Consider times where you managed symptoms, found support, or adapted to challenges.
  - What do those times suggest is important to you?
  - What have you held onto despite Long COVID's presence?

I am too tired to do anything.

Despite challenges, I have found ways to honor my needs and stay connected to my family.

Behavioral Activation

- Behavioral activation focuses on improving mood through behavior changes.[7]
  - Break the cycle of inactivity
  - Engage in activities that provide pleasure, achievement, or connection
  - Regain a sense of control and agency

Key concept: Benefit follows action

Step 1: Identifying Values and Preferred Story

- What's important to you?
- What would your life look like if Long COVID wasn't in control?

- When we shift our focus to what is most important to you, what does your new and preferred story become?

Step 2: Small Steps Toward Activation

- Start with small, manageable actions that fit within your current symptoms.
- Activity types:
  - Pleasure: Activities that make you feel good
  - Mastery: Tasks that give you a sense of achievement
  - Connection: Activities that connect you with others

- Each small action supports the story you want to live, not the one that Long COVID tells.

Step 3: Activity Scheduling

- Why Schedule?
  - Structuring your day helps build momentum and gives you something to look forward to.
- Plan for success:
  - Keep daily activities manageable.
  - Plan around your symptoms/energy levels.
  - Build up activity levels over time.

	Morning	Afternoon
Sun	• Music	• Catch up with a family member
Mon	• Watch a show	• Clean dishes
Tues	• Meditate	• Doctors appt

Step 4: Tracking Your Experience

- Track Activity and Mood
  - Notice how even small actions impact mood, energy, and sense of control over time.
  - Consider how each activity supports your preferred story.

	Afternoon	Enjoy	Energy
Sun	• Catch up with a family member	8	7
Mon	• Clean dishes	6	6
Tues	• Doctors appt	7	3

Grieving Pre-Covid Jenny

Grief, Anxiety & Depression

- Therapy
  - Learning Self Compassion & Patience
  - Meditation & Visualization

UW Medicine

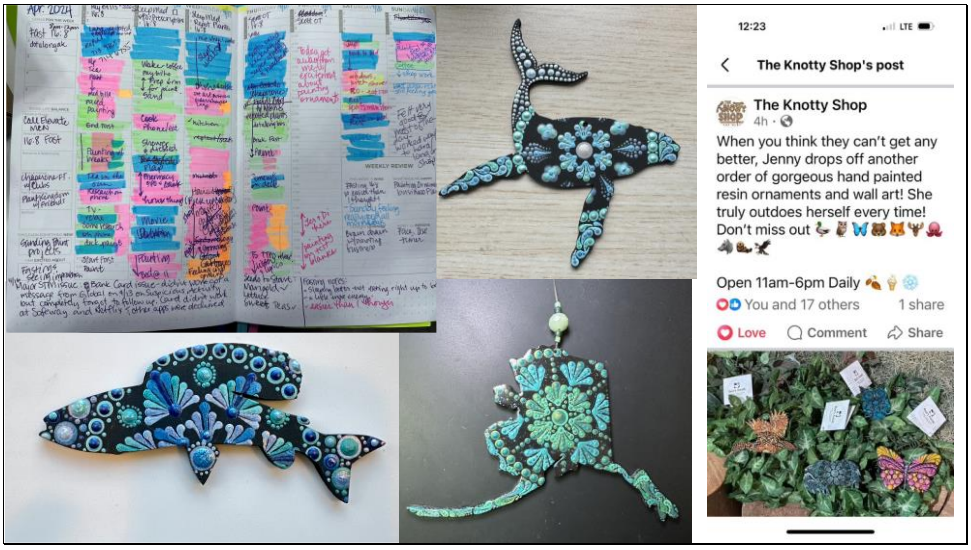
I Value:

- Family
- Creativity
- The Outdoors
- Doing things for others
- Laughter

Leave the world a better place.

Growing with Post-Covid Jenny

- Self Compassion & Gratitude
- Patience & Boundaries
- Learning more each year
- Accepting setbacks & reinfections (up to 6 now)
- Enjoying life in this new body, while staying true to my values.
- Celebrating successes, without comparing to what I could do in the past



Conclusion

- Behavioral activation can be used to help you break free from the limiting story of Long COVID by taking small, meaningful steps toward the life you want.
- The aim isn't to return to the *exact* life you had before, but to create a new narrative that reflects your values and aspirations for the future.

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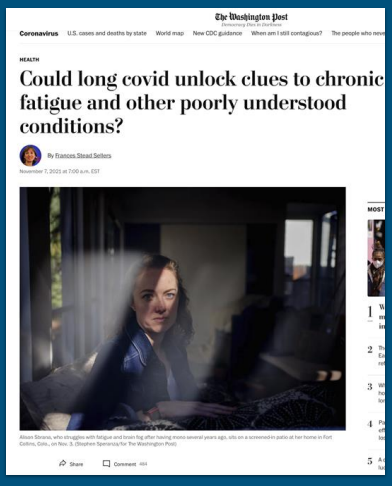
Finding Joy Again

My lived experience: adaptive recreation for energy-limiting chronic illness & disability

Saturday October 12th
Alison Sbrana, Lived Experience Expert

My story

- ***10 years ago I got a virus and never recovered***
- Undiagnosed for several years. Lost community and friends, career, financial stability, and the life I had planned
- Every day was fluctuating and unpredictable. I didn't understand symptoms, or have appropriate medical support
- April 2020: I volunteered for Body Politic supporting thousands of long haulers. Ended up leading their support group for 15k



The Washington Post

Coronavirus U.S. cases and deaths by state World map New CDC guidance When am I still contagious? The people who neve

HEALTH

Could long covid unlock clues to chronic fatigue and other poorly understood conditions?

By Frances Stead Sellers

November 7, 2021 at 7:00 a.m. EST

Alison Sbrana, who struggles with fatigue and brain fog after having mono several years ago, sits on a screened-in patio at her home in Fort Collins, Colo., on Nov. 3. (Stephen Speranza/for The Washington Post)

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MOST

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Loss of recreation, leisure, and socialization

- I lost almost all forms of recreation and leisure I used to engage with when I got sick
- It's hard enough to navigate new normal with loss of abilities, figuring out how to get through each day with medical and basic needs
- But, tolerating all of that hard stuff *without* the ability to engage in leisure, recreation, and social activity is even harder!

What is adaptive recreation?

- Inclusive recreation and leisure activities that are adapted to all kinds of disabilities at any age
- Available from city programs, non-profit orgs, and other programs
- it's about improving our quality of life by making joyful and fun activities accessible and easier for us!

Adaptive recreation for us

- Life with LC and similar chronic illnesses can be really challenging on a daily basis
- It makes it hard for us to engage with basic daily activities – let alone fun things like recreation, leisure, and social activities
- Adaptive recreation helps reduce the energy and barriers for us to participate in fun activities again

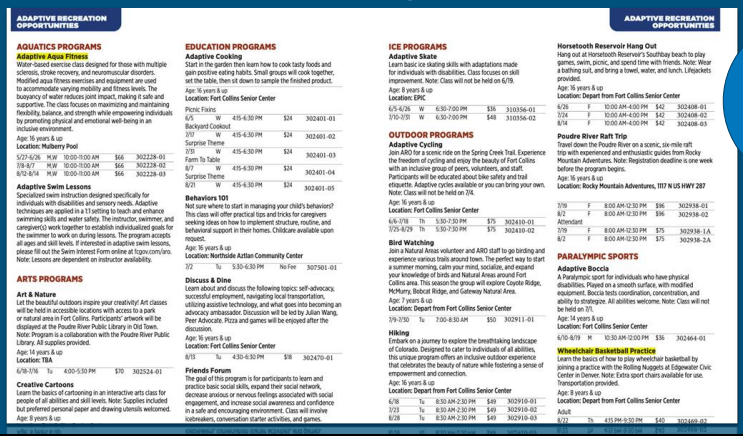
Every one of us deserves to experience joy, have fun, and connect with other people– even with our limited energy!

Feeling comfortable with adaptive recreation

- I needed home services and supports in place to feel comfortable trying adaptive recreation
- I was nervous that it wasn't for people like me, or that I would crash hard after
- Fluctuating, dynamic disability is a disability. We are entitled to these services too
- Occupational therapist encouraged me to try

Adaptive recreation opened up my world again after being homebound!

How did I access adaptive recreation?



ADAPTIVE RECREATION OPPORTUNITIES

AQUATICS PROGRAMS

Adaptive Aqua Fitness

Water-based exercise class designed for those with multiple sclerosis, stroke recovery, and neuromuscular disorders. Modified aqua fitness exercises and equipment are used to accommodate varying mobility and fitness levels. The buoyancy of water reduces joint impact, making it safe and supportive. The class focuses on maximizing and maintaining flexibility, balance, and strength while empowering individuals by promoting physical and emotional well-being in an inclusive environment.

Age: 16 years & up
Location: Mulberry Pool

5/27-6/26	M,W	10:00-11:00 AM	$66	302228-01
7/8-8/7	M,W	10:00-11:00 AM	$66	302228-02
8/12-9/14	M,W	10:00-11:00 AM	$66	302228-03

Adaptive Swim Lessons

Specialized swim instruction designed specifically for individuals with disabilities and sensory needs. Adaptive techniques are applied in a 1:1 setting to teach and enhance swimming skills and water safety. The instructor, swimmer, and caregiver(s) work together to establish individualized goals for the swimmer to work on during lessons. The program accepts all ages and skill levels. If interested in adaptive swim lessons, please fill out the Swim Interest Form online at fcgov.com/aro. Note: Lessons are dependent on instructor availability.

ARTS PROGRAMS

Art & Nature

Let the beautiful outdoors inspire your creativity! Art classes will be held in accessible locations with access to a park or natural area in Fort Collins. Participants' artwork will be displayed at the Poudre River Public Library in Old Town. Note: Program is a collaboration with the Poudre River Public Library. All supplies provided.

Age: 14 years & up
Location: TBA

6/18-7/16	Tu	4:00-5:30 PM	$70	302524-01

Creative Cartoons

Learn the basics of cartooning in an interactive arts class for people of all abilities and skill levels. Note: Supplies included but preferred personal paper and drawing utensils welcomed.

Age: 8 years & up

EDUCATION PROGRAMS

Adaptive Cooking

Start in the garden then learn how to cook tasty foods and gain positive eating habits. Small groups will cook together, set the table, then sit down to sample the finished product.

Age: 16 years & up
Location: Fort Collins Senior Center

Picnic Fixins				
6/5	W	4:15-6:30 PM	$24	302401-01
Backyard Cookout				
7/17	W	4:15-6:30 PM	$24	302401-02
Surprise Theme				
7/31	W	4:15-6:30 PM	$24	302401-03
Farm To Table				
8/7	W	4:15-6:30 PM	$24	302401-04
Surprise Theme				
8/21	W	4:15-6:30 PM	$24	302401-05

Behaviors 101

Not sure where to start in managing your child's behaviors? This class will offer practical tips and tricks for caregivers seeking ideas on how to implement structure, routine, and behavioral support in their homes. Childcare available upon request.

Age: 16 years & up
Location: Northside Aztlan Community Center

7/2	Tu	5:30-6:30 PM	No Fee	307501-01

Discuss & Dine

Learn about and discuss the following topics: self-advocacy, successful employment, navigating local transportation, utilizing assistive technology, and what goes into becoming an advocacy ambassador. Discussion will be led by Julian Wang, Peer Advocate. Pizza and games will be enjoyed after the discussion.

Age: 16 years & up
Location: Fort Collins Senior Center

6/15	Tu	4:30-6:30 PM	$18	302470-01

Friends Forum

The goal of this program is for participants to learn and practice basic social skills, expand their social network, decrease anxious or nervous feelings associated with social engagement, and increase social awareness and confidence in a safe and encouraging environment. Class will involve icebreakers, conversation starter activities, and games.

ICE PROGRAMS

Adaptive Skate

Learn basic ice skating skills with adaptations made for individuals with disabilities. Class focuses on skill improvement. Note: Class will not be held on 6/19.

Age: 8 years & up
Location: EPIC

6/5-6/26	W	6:30-7:00 PM	$36	310356-01
7/10-7/31	W	6:30-7:00 PM	$48	310356-02

OUTDOOR PROGRAMS

Adaptive Cycling

Join ARO for a scenic ride on the Spring Creek Trail. Experience the freedom of cycling and enjoy the beauty of Fort Collins with an inclusive group of peers, volunteers, and staff. Participants will be educated about bike safety and trail etiquette. Adaptive cycles available or you can bring your own. Note: Class will not be held on 7/4.

Age: 16 years & up
Location: Fort Collins Senior Center

6/6-7/18	Th	5:30-7:30 PM	$75	302410-01
7/25-8/29	Th	5:30-7:30 PM	$75	302410-02

Bird Watching

Join a Natural Areas volunteer and ARO staff to go birding and experience various trails around town. The perfect way to start a summer morning, calm your mind, socialize, and expand your knowledge of birds and Natural Areas around Fort Collins area. This season the group will explore Coyote Ridge, McMurry, Bobcat Ridge, and Gateway Natural Area.

Age: 7 years & up
Location: Depart from Fort Collins Senior Center

7/9-7/30	Tu	7:00-8:30 AM	$50	302911-01

Hiking

Embark on a journey to explore the breathtaking landscape of Colorado. Designed to cater to individuals of all abilities, this unique program offers an inclusive outdoor experience that celebrates the beauty of nature while fostering a sense of empowerment and connection.

Age: 16 years & up
Location: Depart from Fort Collins Senior Center

6/18	Tu	8:30 AM-2:30 PM	$49	302910-01
7/23	Tu	8:30 AM-2:30 PM	$49	302910-02
8/28	Tu	8:30 AM-2:30 PM	$49	302910-03

ADAPTIVE RECREATION OPPORTUNITIES

Horsetooth Reservoir Hang Out

Hang out at Horsetooth Reservoir's Southbay beach to play games, swim, picnic, and spend time with friends. Note: Wear a bathing suit, and bring a towel, water, and lunch. Lifejackets provided.

Age: 16 years & up
Location: Depart from Fort Collins Senior Center

6/26	F	10:00 AM-4:00 PM	$42	302408-01
7/24	F	10:00 AM-4:00 PM	$42	302408-02
8/14	F	10:00 AM-4:00 PM	$42	302408-03

Poudre River Raft Trip

Travel down the Poudre River on a scenic, six-mile raft trip with experienced and enthusiastic guides from Rocky Mountain Adventures. Note: Registration deadline is one week before the program begins.

Age: 16 years & up
Location: Rocky Mountain Adventures, 1117 N US HWY 287

7/19	F	8:00 AM-12:30 PM	$96	302938-01
8/2	F	8:00 AM-12:30 PM	$96	302938-02
Attendant				
7/19	F	8:00 AM-12:30 PM	$75	302938-1A
8/2	F	8:00 AM-12:30 PM	$75	302938-2A

PARALYMPIC SPORTS

Adaptive Boccia

A Paralympic sport for individuals who have physical disabilities. Played on a smooth surface, with modified equipment. Boccia tests coordination, concentration, and ability to strategize. All abilities welcome. Note: Class will not be held on 7/1.

Age: 14 years & up
Location: Fort Collins Senior Center

6/10-8/19	M	10:30 AM-12:00 PM	$36	302464-01

Wheelchair Basketball Practice

Learn the basics of how to play wheelchair basketball by joining a practice with the Rolling Nuggets at Edgewater Civic Center in Denver. Note: Extra sport chairs available for use. Transportation provided.

Age: 8 years & up
Location: Depart from Fort Collins Senior Center

Adult				
8/22	Th	4:15 PM-9:30 PM	$40	302468-02

Look for scholarships & reduced fee programs

Look at city programs & local or statewide nonprofits

Adaptive cycling

- I live in a platinum bike city, but I hadn't been on a real bike for 8 years since I got sick. I didn't think biking would ever be possible for me again
- **I paid $2.88 total** for this 8 week adaptive cycling class from our city, including equipment (adaptive bike and helmet)

Adaptive cycling: a family outing!

In Grand Teton National Park, e-biking with family

- I hadn't been able to participate in family vacation activities for almost a decade
- My family wanted to be able to include me in activities, but before adaptive recreation, we didn't know how to do that. So we didn't do any family vacations for almost a decade
- Now I could participate in something equally thanks to adaptive recreation!

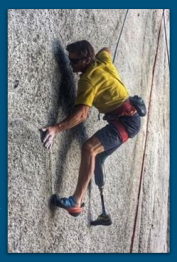
Adaptive cycling: How did we adapt?

Per recreational therapists who run the program:

- I started with upright electric assist tricycle
  - Upright tricycle for balance and ergonomics
  - E-assist to ease fatigue/POTS
  - Plus bluetooth heart rate monitor to alarm me if I need to increase e-assist or take a break
- Then I tried electric-assist recumbent mountain bike through nearby county program

Adaptive rock climbing

- I paid **$15.31 total** for this 8 week class (including gear rental!) because of our city reduced fee pass
- A Denver-based adaptive sports group sent their adaptive climbing expert to support us and offer specialized advice



How did we adapt?

While climbing:

- Extra time on the wall
- Heart rate monitor
- Reduce sensory overwhelm by climbing at off-times
- Belayer adaptations - keeping me tight, no slack

On the ground:

- Use my rollator, even when belaying
- Belay device with safety protection
- Gloves to reduce sensory input from rope
- Feeling the tension of the rope to know when to pull in slack

Art & Nature Class

- A great example of adaptive or accessible leisure activity. Not all adaptive recreation is fast-paced!
- I paid **$6.10 total** for this 6 week class (including supplies) because of reduced fee program
- They provided all supplies, cleaned up after us, and planned all the projects. *Big energy saver! This is part of what makes it accessible for us*

Art & Nature Class

- Located at accessible locations in town with nature views
- Taught by an occupational therapist
- Materials and clean-up taken care of

Adaptive river rafting

Where I live, this river runs through town and is the center of our culture and history.

Adaptive river rafting: How did we adapt?

Per recreational therapists who run the program:

- Everyone in my raft besides me were strong paddlers, so I didn't have to paddle at all
- They installed a handle in the center for me to hold
- I could sit down on the floor of the raft to save energy
- They placed me in the middle row of the raft for safety
- I rented additional wetsuit gear for temperature management

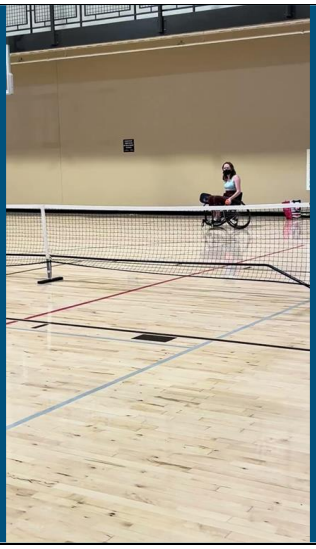
Adaptive Snow Tubing

How we adapted:

- Recreation therapists investigated accessibility and communicated our accommodations with facility
- Extra time & help to get me seated in tube before the lift pulls me up
- Help carrying tube back to lift
- Frequent breaks, space to warm up
- Riding in my own car for comfort & symptom management

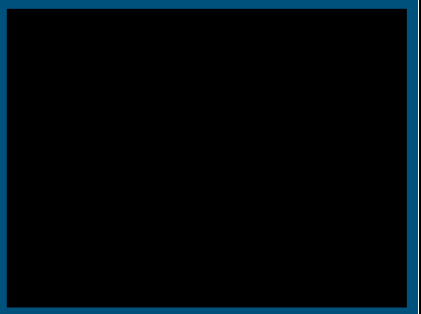
Adaptive pickleball

- Paralympic athlete did a one-time adaptive pickleball event in our area
- I have never played pickleball, tennis, or anything like this
- I was able to play a whole game of pickleball by the end of the night!



Adaptive Pickleball: How did we adapt?

- They provided all equipment – I showed up!
- We get an extra bounce (2 instead of 1)
- I used one of their sport wheelchairs
  - Being seated conserves energy and manages heart rate
  - Allowed me to participate for 2 hours!



How to find adaptive recreation opportunities?

- Search "Adaptive Recreation + Your City" (or nearest city)
- Look for city or county recreation programs that are inclusive of disabilities
- Look for non-profit orgs. Some focus on specialty sports or populations
- *Make sure to look for low income programs or scholarships!*

Free adaptive cycling program returns this summer with Outdoors for All!

by Maddie Dewhirst on April 25, 2023

Left: A cyclist enjoys a ride on one of Outdoors for All's trikes. Right: A cyclist uses a handcycle. Photo credit: Outdoors for All

Seattle options: adaptive cycling, adaptive climbing, adaptive skiing, adaptive kayaking, power soccer, sled hockey, wheelchair basketball, goalball, adaptive circus arts +

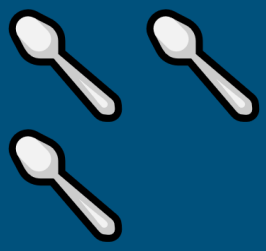
Inclusivity: a bonus of adaptive recreation

- understanding & flexibility from everyone involved
- Peers: our disabilities may vary, that's okay. All kinds of support & access needs welcome here
- Recreation therapists & staff responsible for accessibility & coordinating support needs

With adaptive recreation, the burden is NOT on us to figure out accessibility, accommodations, or extra help for us to participate. This is part of what makes adaptive recreation great for us!

Varied levels of disability & support needs

- Different folks in our community have varied levels of disability, and support needs
- My hope: there are various activities and adaptations to meet everyone where they are at
  - Adaptive rec programs get creative all the time to adapt to varying needs!
- This is *not* about pushing people past their comfort zone, or energy envelope. **It's about bringing joy to our community in an easier, more accessible way to stay *within* their energy level**

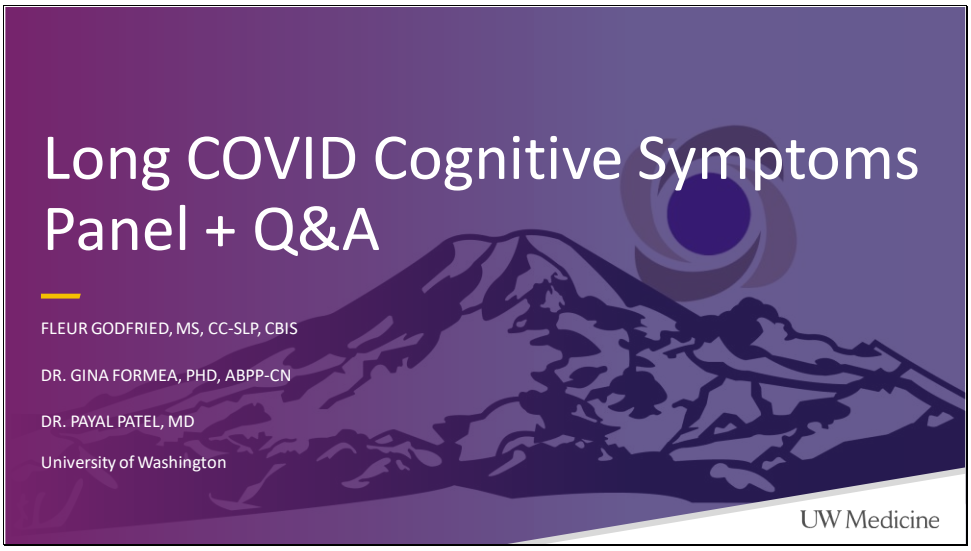


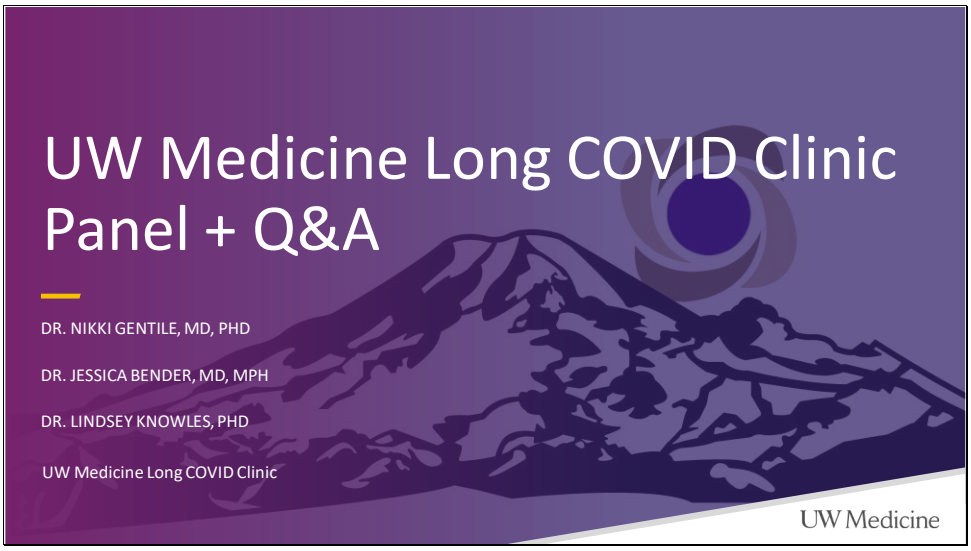
Adaptive Recreation helps us access joy again, safely!

- Social, leisure, and recreational activities are important to a full and balanced life. Long COVID makes it hard to do these!
- Adaptive recreation makes it easier and safer for us to access, so we can have fun again while continuing to manage our symptoms
- Scholarship & reduced fee programs can make it easy and affordable to access

Questions or comments?

AlisonSbrana@gmail.com


Long COVID Cognitive Symptoms Panel + Q&A
FLEUR GODFRIED, MS, CC-SLP, CBIS
DR. GINA FORMEA, PHD, ABPP-CN
DR. PAYAL PATEL, MD
University of Washington
UW Medicine


UW Medicine Long COVID Clinic Panel + Q&A
DR. NIKKI GENTILE, MD, PHD
DR. JESSICA BENDER, MD, MPH
DR. LINDSEY KNOWLES, PHD
UW Medicine Long COVID Clinic
UW Medicine


THANK YOU FOR JOINING US
• A recording of the symposium will be available on our website in one week.
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