

Maryland Advisory Council on Health and Wellness Meeting Minutes
January 17, 2024, 4-6:00PM

Members Present

Andrew Baker
Crystal Bell
Felicia Brannon
Tara Clemons Johnson
Leigh Ann Eagle
Jennifer Eastman
Mychelle Farmer
Gary Gerstenblith
Roger Harrell
Darryl Heggans
Seth Martin
Lusi Martin-Braswell
Jared Meacham
Mallory Mouradjian
Aruna Nathan
Rachel Pigott
Jason Semanoff
Marsha Seidelman
Teresa Titus-Howard
Vaple Robinson
Pamela Williams
Pamela Xenakis
Sam Zisow-McClean

Members Not Present

Salliann Alborn
Mary Backley
Jonathan Dayton

MDH Staff Present

Jennifer Faulkner
Ali MacStudy
Olivia Massa
Kristi Pier
Christa Thornton

Members of the Public Present

None

I. Open Maryland Advisory Council on Health and Wellness

Teresa Titus-Howard, Chair

Dr. Titus-Howard called the meeting to order at 4:02pm and welcomed members. She provided a review of the agenda, and asked Ms. Pier to complete the roll call. She asked for a review of the October 18, 2023 minutes; Jared Meacham and Roger Harrell motioned to approve the minutes, there were no dissents.

II. MEAction and Long COVID

Dr. Titus-Howard introduced members of MEAction, Whitney Fox, Gwynn Dujardin and Bridget Collins.

MEAction Maryland advocates for awareness, recognition, care and support for Myalgic Encephalomyelitis (ME), Long Covid and associated conditions. The • #MEAction vision “is a world where people with ME are believed, supported by systems that work and have access to effective medical treatments.”

The MEAction team presented on ME and Long Covid, presentation attached. The presentation generated appreciation from the Council members.

III. 2024 Legislative Session Update

Teresa Titus-Howard and Kristi Pier stated there was one Tuesday meeting to review legislation, and the ad hoc committee is reviewing legislation to bring forward to the full Council.

IV. Public Comment

No members of the public present provided comments.

V. Adjourn Full Meeting at 4:58pm.

VI. Transition to Virtual Committee Meetings at 4:58pm.

The full council transitioned to committee meetings.

Prepared for:

MD Council of Health & Wellness

By: #MEAction

Maryland State Chapter



MARYLAND



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Outline

#MEACTION MARYLAND

**LONG COVID & ASSOCIATED
CONDITIONS**

IMPACTS ON MARYLAND

PATIENT EXPERIENCE

**HELP MARYLANDERS WITH
LONG COVID**





MARYLAND

- **We advocate for awareness, recognition, care & support for Myalgic Encephalomyelitis (ME), Long Covid & associated conditions**
- **#MEAction’s “vision is a world where people with ME are believed, supported by systems that work & have access to effective medical treatments.”**

Why is ME important?

ME is often, but not always, triggered by an infection.

Prevalence has increased from up to 2.5 million Americans in 2020 to as many as 9 million Americans today.

Up to 46% of people with Long Covid qualify for an ME diagnosis.

PEM/PESE: Cardinal Symptom of ME & LC

- Only part of the official diagnostic criteria for ME & LC
- “Flare in symptoms or appears of new symptoms after exertion, often manifesting after a 24hour delay”
- Can be caused by:
 - Physical activity
 - Cognitive overexertion
 - Sensory overload
- CPET monitoring has shown impaired O2 extraction in proportion to the severity of symptoms
 - distinguishing PEM from deconditioning

Post-exertional malaise (PEM)

PEM is an increase in the severity of symptoms and/or the appearance of new symptoms after physical or cognitive exertion, often manifesting after a characteristic 24-hour delay. However, 12-48 hours is common. Some symptoms that may be part of PEM presentation are outlined below, with common-language descriptions.

Sensory

New or increased sensitivity to light, sounds, smell or temperature

Autonomic

Nausea
Vertigo, dizziness
Increased sighing & yawning
Drop in core temperature
“The shakes”
Heart pounding

Cognitive

Can't process words
Trouble retrieving words
Thinking is effortful
“brain fog”,
Trouble starting & changing tasks

Pain

Headache, aches and pains,
Pain where the skull meets the spine

Immune

Flu-like symptoms
Fever, sore throat
swollen lymph nodes

Neuromuscular

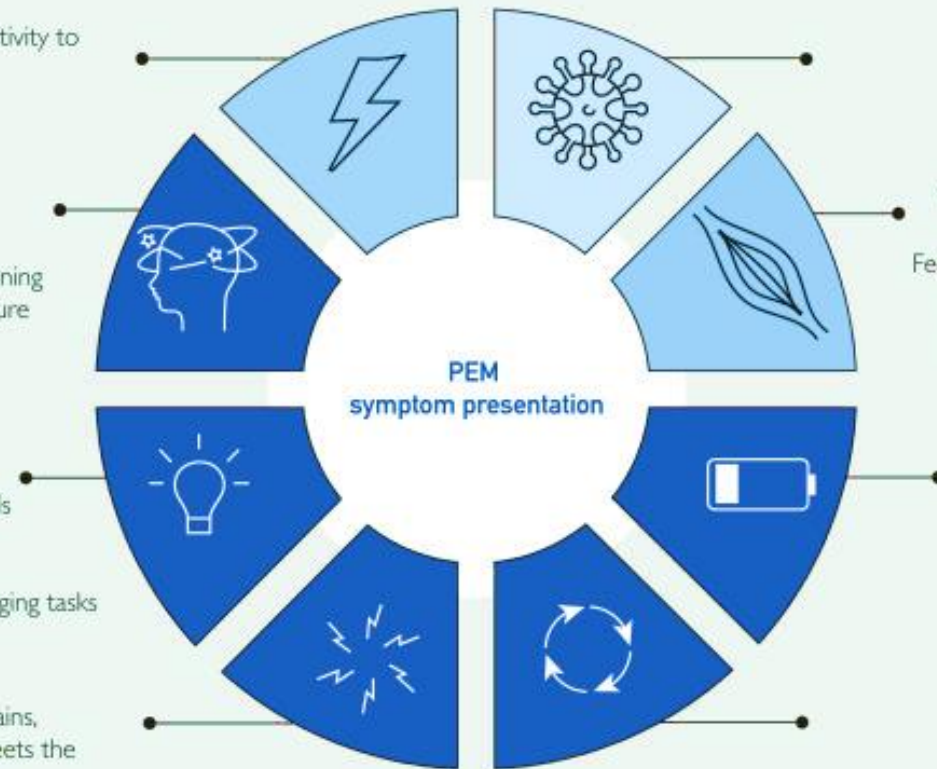
Muscles less responsive/
non-responsive
Feels “heavy”, “leaden”, like
“wet concrete”
Muscles painful, burning
tingling or ‘buzzing’

Energy level

A falling, pooling, or
“pulled plug” sinking
sensation
in “shutdown”
“locked in my body”
“my battery is low”
“wired but tired”

Metabolism

Feeling “poisoned”
“like a hangover”



PEM is not:

- Being more tired than usual after activity
- Deconditioning
- Second-day muscle soreness
- Necessarily relieved by sleep

Acute Covid

- CDC → Symptoms may appear 2 – 14 days after exposure
 - Symptoms may change with new variants
- Acute interventions include rest, Paxlovid, antihistamines & OTC medications
- Can cause long-term effects
- Risk of long-term effects increases with each reinfection

Approximately **1 in 5 adults** ages 18+ have a health condition that might be related to their previous COVID-19 illness, such as:

- Neurologic and mental health conditions*
- Cardiovascular conditions
- Kidney failure
- Respiratory conditions
- Musculoskeletal conditions
- Blood clots and vascular issues

Talk to your health care provider if you have symptoms after COVID-19

MAY 24, 2022

* Adults aged 65 and older at increased risk

MYTH: “It’s just a cold”

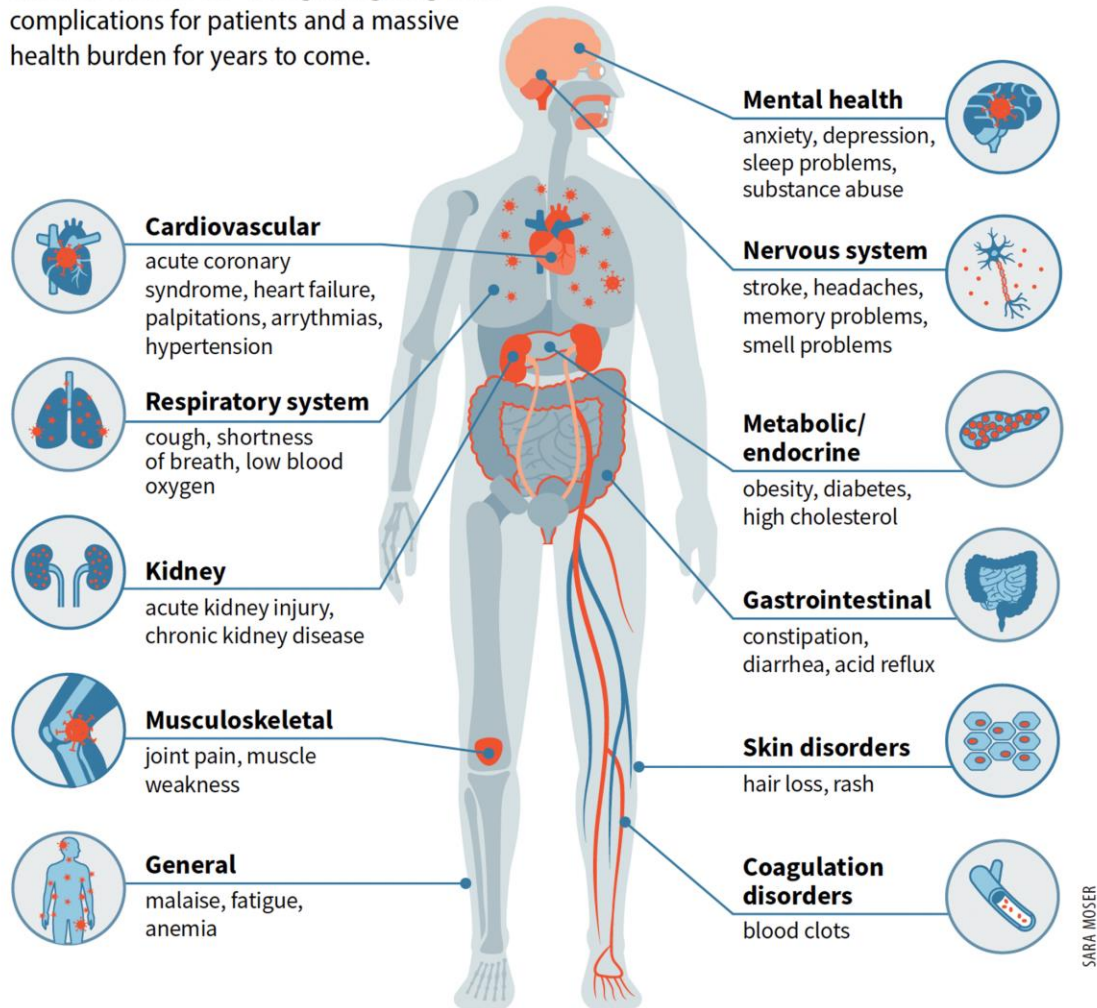
Covid-19 can:

- Affect all body systems
- Trigger permanent symptoms
- Trigger other health conditions (such as diabetes or kidney disease)

COVID-19: Lasting impact

Even those survivors with mild initial cases can have wide-ranging health issues for ~~six months~~ or more.
two years

WashU researchers have linked many diseases with COVID-19, signaling long-term complications for patients and a massive health burden for years to come.

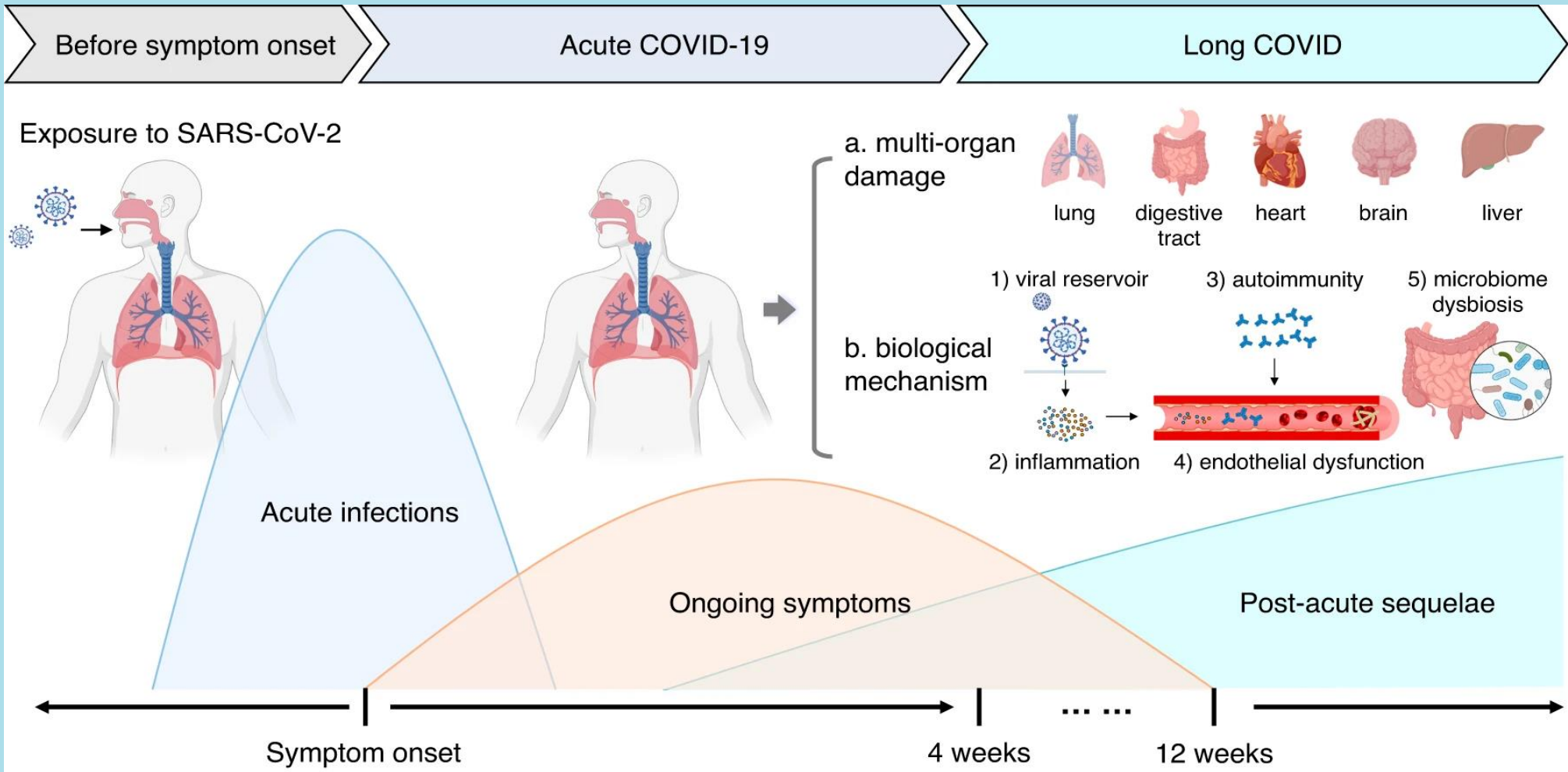


*Eric Topol substack

Long Covid

- CDC → ≥ 4 weeks after Covid
- >200 symptoms
- Heterogenous Population
- US Census: More likely to affect:
 - Hispanic and Black Americans
 - Women, Transgender and non-binary Americans
 - Low-income Americans
- Multiple Comorbidities: MCAS, SFN, POTS/OI, IBS, EDS
- “People think that it is Long Covid, but it is **FOREVER Covid**”
- No treatment → No prognosis

Covid-19 Illness Progression



*Li, Jingwei, et al. "The long-term health outcomes, pathophysiological mechanisms and multidisciplinary management of Long Covid." *Signal Transduction and Targeted Therapy*, vol. 8, no. 1, 2023,

Maryland
population

6,164,660





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659,618 – 974,016 Adults in Maryland who have experienced Long COVID

10.7 – 15.8% of adults in Maryland have experienced Long Covid*

* according to [CDC Household Pulse Survey](#) results from 10/30/23



**Adults in Maryland with
Long COVID could fill
M&T Bank stadium**

**9 – 13 times
(71,008 capacity)**

In the entire U.S. there are only 21 physicians who treat ME/CFS, one common condition associated with Long Covid. During a football game, there are **22 men** on the field.

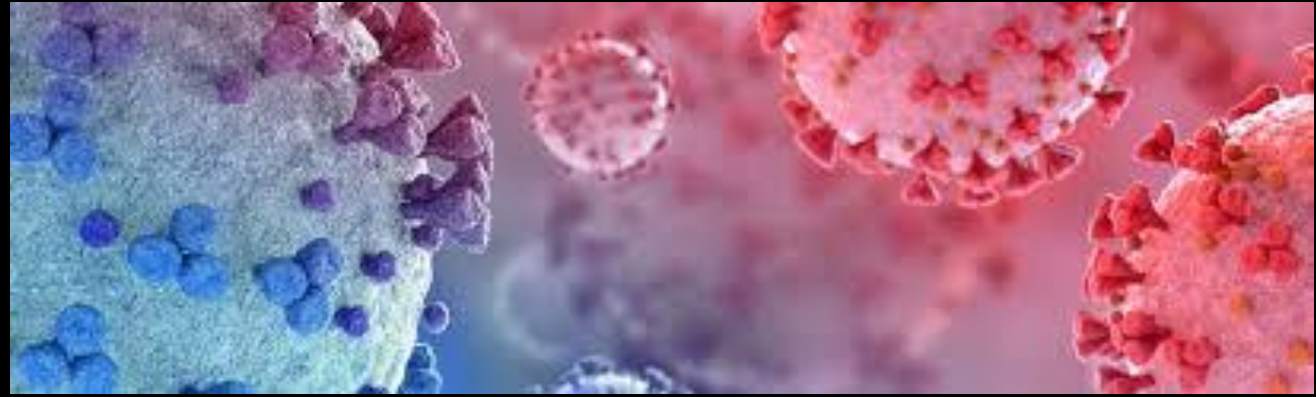
The Current Surge

Estimates show **1 in 3*** US may become infected during this surge

2 million Marylanders may be infected or reinfected during the current surge

400,000 may lead to Long Covid

200,000 may lead to ME/CFS



In just a few weeks, we could be looking at
1.06 million – 1.374 million

Adults in Maryland who are experiencing
Long COVID

*Source: Pandemic Mitigation Collaborative

Long Covid in Children: the Forgotten Demographic



- In a nasal swab study, **75%** of Covid-positive children were asymptomatic¹
- Nearly **25%** of asymptomatic children are showing long-term symptoms²
- Children are an **established risk group** that typically experience significant morbidity from many respiratory viruses¹
- Schools ranked highest as public sources of exposure¹
- **75%** of Baltimore City schools and **30%** of Baltimore County schools earned the lowest score on **chronic absenteeism** measures³

- **We don't want to see the next generation of Maryland children to grow up with Long Covid disability**

1. Kelso, John M. "Risk factors for SARS-COV-2 infection and transmission in households with children with asthma and allergy: A prospective surveillance study." *Pediatrics*, vol. 152, no. Supplement 3, 2023
2. Buonsenso, Danilo, et al. "Preliminary evidence on Long Covid in children." *Acta Paediatrica*, vol. 110, no. 7, 2021, pp. 2208–2211,
3. Hatch, Bri. "Maryland Schools Struggle with Absenteeism, Social Studies Proficiency, State Report Cards Say." *WYPR*, 13 Dec. 2023.



Difficulty finding health care providers & long wait lists



Healthcare Providers don't know what tests to run or how to diagnose such wide-ranging symptoms



Lack of information from reputable online sources & health agencies



Relying on fellow patients for support navigating healthcare systems & managing symptoms

The Patient Experience

“Nobody warned me that this could happen.”

Where can Maryland residents go for information and support?



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Equip MD HCW with info to **recognize, diagnose & treat** LC, ME/CFS & associated conditions



Provide **comprehensive information** about Long Covid, ME & associated conditions on the MDH website



Provide **lists of HCW** who treat various conditions associated with Long Covid



Connect patients to **support groups & resources** from reputable providers

How You Can Respond

Approaches to Long Covid/ME Patient

EXERTION MANAGEMENT

Stop. Rest. Pace.

Reduce and avoid triggers of Post-Exertion Malaise (PEM)

LIFESTYLE INTERVENTIONS

- **CARDIOVASCULAR:** pace exertion>> stretching & breathing, movement
- **ORTHOSTATIC:** salt & fluids; compression clothing; mobility supports
- **COGNITIVE:** memory aids; writing, journaling
- **SENSORY:** noise cancelling headphones; dark glasses; scent retraining
- **DIGESTIVE:** antihistamine & anti-inflammatory diet, small meals

Partner with an informed provider to investigate all symptoms for potential system & organ damage; diagnose and prescribe for symptom management and care support

Approaches to Long Covid HC Providers

Management considerations
adapted from: Grach, Seltzer
(2023)

Mayo Clinic Proceedings

RECOGNIZE COMPLAINTS

- Consider “subjective” symptoms often mistaken for *anxiety* and/or *deconditioning* as potential infection-associated illness
- Consult our CLINICIAN PACKAGE for Mayo and expert guidance

CONSIDER PRESCRIPTION INTERVENTIONS

- ORTHOSTATIC: fludrocortisone; midodrine; propranolol; pyridostigmine
- COGNITIVE: L-D Naltrexone, L-D Abilify, *careful use of stimulants
- PAIN & NEUROPATHY: pregabalin, duloxetine, gabapentin
- SLEEP: melatonin, trazodone, suvorexant, doxepin

Support sick leave and disability claims for patients no longer able to work and/or care for themselves or others. Chronic illness disability often leads to poverty, which contributes to poorer health outcomes.

Direct patients to state and online resources for information and support.

Approaches to Long Covid By Symptom

Management considerations
adapted from: Grach, Seltzer (2023)
[Mayo Clinic Proceedings](#)

Fatigue:

LDN, LDA, treat vitamin deficiencies, anti-inflammatory diet

Sleep Issues:

melatonin, trazodone, suvorexant, doxepin/tricyclic antidepressants, gabapentin/pregabalin

Cognitive Dysfunction:

journaling, memory aids, OT, LDN, LDA, careful use of stimulants

Sensory Amplification:

noise-cancelling headphones, tinted glasses, crowd exposure reduction, LDA

GI Symptoms:

anti-inflammatory diets, antihistamines, small meals, pro/symbiotics, fiber or motility agents

Orthostatic Intolerance:

fluids/electrolytes/compression, fludrocortisone, midodrine, propranolol, pyridostigmine, guanfacine (POTS subtype)

Dizziness:

Vestibular therapy, low-dose SSRI or SNRI

Muscle or Joint Pain:

OTC medications, duloxetine, milnacipran, pregabalin, gabapentin, TCAs, LDN

Neuropathy:

pregabalin, gabapentin, TCAs, compression or brace therapy

Approaches to Long Covid State & Online Resources

EXISTING MARYLAND RESOURCES

Most informative and comprehensive: **Carroll County HD**
Includes symptoms and links to resources



EDUCATION & CME TRAINING

Bateman Horne Center & Workwell Foundation

Bateman Horne PEM Video Series Post-Exertional Malaise

Long Covid BHC Project ECHO (providers)
Schmidt Initiative for Long Covid Echo Series



WORK ACCOMMODATIONS & DISABILITY

US Dept. HHS & SSA

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



Disability Determination

Job Accommodation Network: Ask JAN

Have questions about workplace accommodations and the Americans with Disabilities Act (ADA)?

[Ask JAN! We can help.](#)



PATIENT PEER SUPPORT

Online connection & resource sharing



Thank You MD Council of Health & Wellness!

- We will be sharing the following resources:
 - ME/CFS & Long Covid Clinician Package
 - PDF copy of our slides

- We look forward to your questions

- Please feel free to follow up:

Maryland@MEAction.net





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MARYLAND@MEACTION.NET

	Individual	Costs for LC in MD	Costs for ME in MD
Reduced quality of life	\$100,000.00	\$41,140,000,000.00	\$25,656,400,000.00
Reduced earnings	\$1,100.00	\$452,540,000.00	\$282,220,400.00
Increased medical spending	\$8,731.00	\$411,400.00	\$2,240,060,284.00
	\$109,831.00	\$41,592,951,400.00	\$28,178,680,684.00

Total cost of LC and ME in the State of MD
\$69,771,632,084.00

Number of Marylanders with Long Covid (low estimate from 2022)	411,400
Number of Marylanders with MEcfs (estimate from 2022)	256,564

Financial Impact for Marylanders

[“The Cost of Living with Long Covid” by David Cutler \(Harvard\)](#)



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Real Terms For Marylanders

- **We're 10 percentage points less likely to be employed**
- **Work 50% fewer hours**
- **Experienced greater impact in their employment status and work hours**