

# ME/CFS

Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome

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BACKGROUND INFORMATION

PREPARED FOR HHS ASSISTANT SECRETARY OF HEALTH, DR. RACHEL LEVINE  
AUGUST 20, 2021

# The Myalgic Encephalomyelitis Action Network (#MEAction)



[\*\*#MEAction\*\*](#) is an advocacy organization that fights for research, medical education, and public recognition of myalgic encephalomyelitis/chronic fatigue syndrome so that one day, people with ME will have access to compassionate and effective clinical care.

“

An entire community had been ignored by medicine and had missed out on the last 30 years of science. A part of the problem is that many of us are literally too ill to leave our home and so doctors and the broader public rarely see us.”

— Jennifer Brea, Co-founder, #MEAction



# The Devastation of ME/CFS

## **Myalgic Encephalomyelitis / Chronic Fatigue**

**Syndrome (ME/CFS)** is a chronic, complex, systemic disease that can profoundly affect the health and productivity of affected patients.

**1 – 2.5 million** Americans  
estimated to be living with  
ME/CFS



# The Devastation of ME/CFS

- 75% are women
- 25% housebound or bedbound
- 75% can't work
- \$36 - 51 billion annual economic impact
- 84–91% undiagnosed or misdiagnosed
- 30% took >5 years to be diagnosed
- Recovery is rare

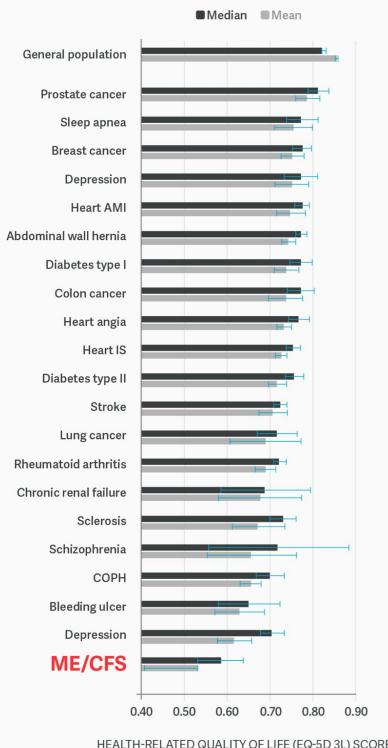


# Not a Death Sentence, But a Life Sentence

People with ME/CFS have lower mean/median quality of life (QOL) scores than:

- **congestive heart failure**
- **hypertension**
- **multiple sclerosis**
- **end-stage renal disease**

ME/CFS health-related quality of life compared to other conditions



The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). PLOS ONE 10(7): e0132421.

<https://doi.org/10.1371/journal.pone.0132421>

# ME/CFS is Not “Feeling Tired”

- Neurological, immunological, and metabolism impairment
- Significant cognitive impairment
- Autonomic dysfunction
- Profound exhaustion
- Unrelenting, sometimes completely debilitating, pain
- Hallmark symptom is **post-exertional malaise** (PEM), a significant and prolonged worsening of symptoms and/or the appearance of new symptoms after sustained physical or mental activity. Overexertion can damage a patient's health, sometimes permanently.



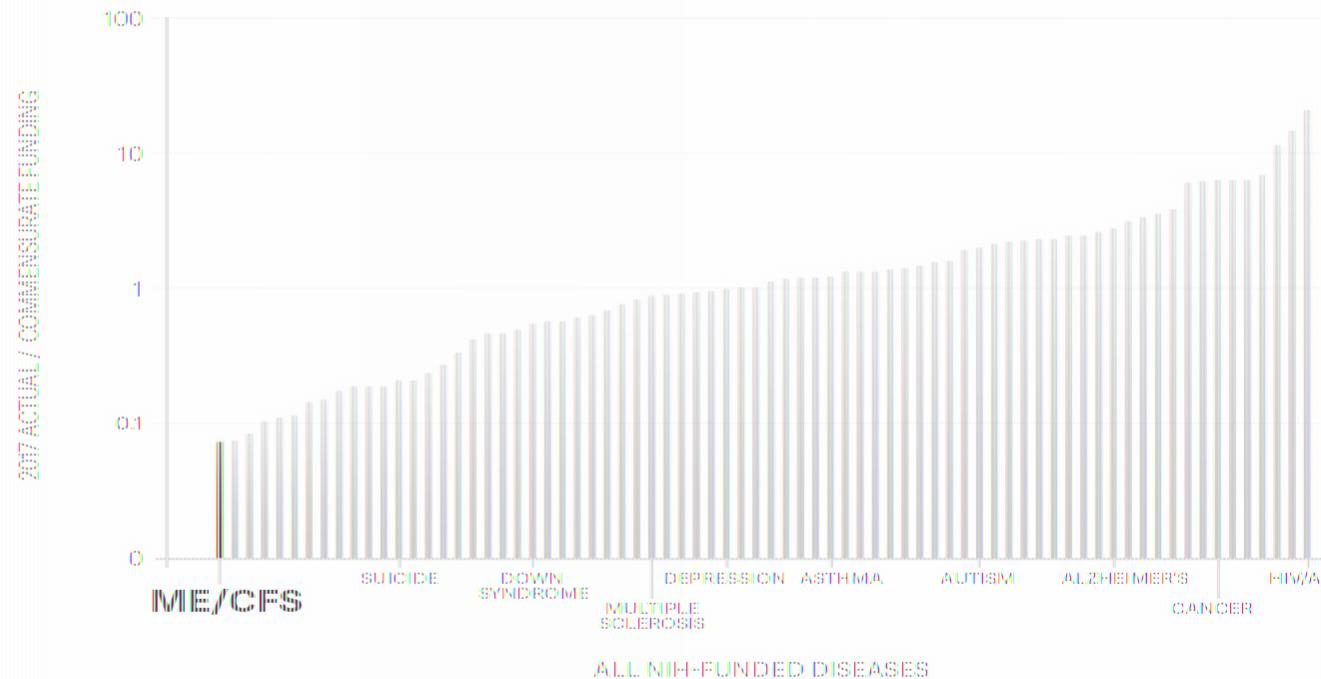
*Whitney Dafoe has severe ME/CFS. He is bedridden and has lost the ability to speak or eat on his own. He is fed exclusively with a jejunostomy tube into his small intestine.*

No diagnostics

**No FDA-approved treatments**

No cure

# Ratio of Actual Funding to Burden-Commensurate Funding of All Diseases Funded by NIH (2017)



Mirin, A., Dimmock, M., & Jason, L. (2020). Research update: The relation between ME/CFS disease burden and research funding in the USA. *Work*, 66(2), 277–282. <https://content.iospress.com/articles/work/wor203173>.

## Daisy Long: 14 years old



*An award-winning rower at the age of 12 with a keen love of the outdoors, Daisy's life changed immensely since she fell ill.*



“

It's fainting all the time and vomiting when you get out of bed... On the rare occasion I have the strength to go out with friends to escape the house for extended periods of time I have to use a wheelchair. I walk so slowly and feel so weak..."

And yet, often  
family, friends  
and even doctors  
**do not believe**  
they are ill.

# The Misunderstanding of ME/CFS

- Medical attitudes toward ME/CFS today are comparable to the disbelief and stigma surrounding MS and Autism 30 years ago
  - Autism was blamed on mothers who were insufficiently affectionate
  - Multiple Sclerosis was derided as a disorder of nerves and insecurity
- ME/CFS, mislabeled as psychological, “deconditioning,” or “fear of activity,” resulting in misleading science and potentially harmful therapies

# Why has this disease been neglected for over 30 years?

A poorly defined, complex disease that is difficult to diagnose

- A multisystem disease with difficult-to-measure symptoms and no biomarkers
- Case definitions are too broad and include patients who do not have the disease

Incorrectly viewed, studied, and treated as a psychological illness

- Most commonly studied and recommended treatments based on this assumption
- Patients still face the challenge of “proving” they are sick

SOURCE: Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness, NAM 2015

# Why has this disease been neglected? (continued)

## The disease has been highly stigmatized

- Patients commonly told, even by medical professionals, “it’s all in your head...Get over it...Buck up”
- Researchers have been discouraged by academic centers from studying the disease

## The name, “Chronic Fatigue Syndrome,” is difficult to take seriously

- Diseases are not usually named for a single non-specific symptom. i.e. lung cancer is not “Chronic Coughing Syndrome”
- This inappropriate and insulting name has contributed to the lack of credibility.

SOURCE: Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness, NAM 2015

# Why has this disease been neglected? (continued)

Most medical professionals have little understanding of ME/CFS

- Less than 1/3 of medical schools include ME/CFS in their curriculum
- Current medical guidance for physicians is incorrect and utilizes outdated or disproven information

SOURCE: Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness, NAM 2015

How does ME/CFS relate to  
Long COVID?

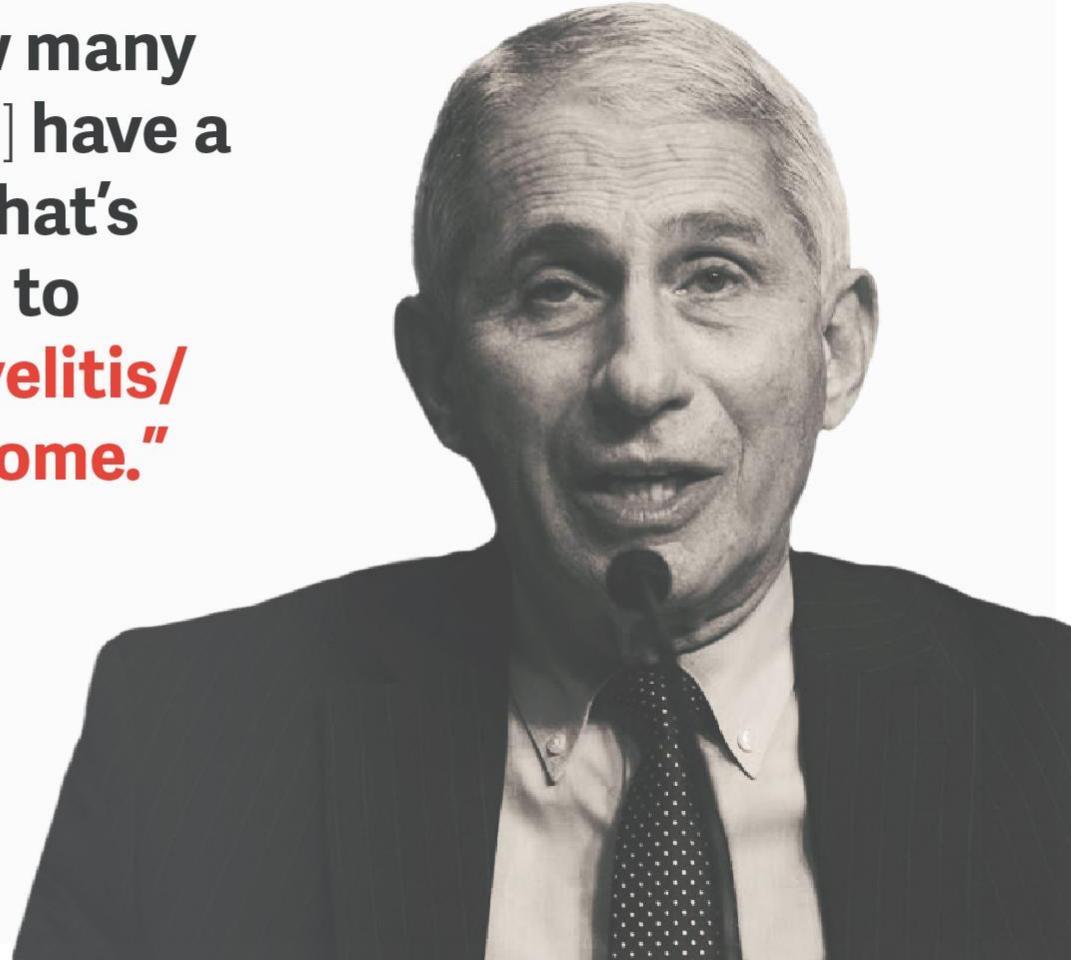
“

**It's extraordinary how many people [with Covid-19] have a post-viral syndrome that's very strikingly similar to myalgic encephalomyelitis/ chronic fatigue syndrome.”**

— DR. ANTHONY FAUCI

DIRECTOR, NIAID, NATIONAL INSTITUTES OF HEALTH  
MEMBER, WHITE HOUSE CORONAVIRUS TASKFORCE

*Topol E., Verghese A. “Fauci to Medscape: ‘We’re All In It Together...’” Medscape (July 17, 2020). [https://www.medscape.com/viewarticle/933619#vp\\_3](https://www.medscape.com/viewarticle/933619#vp_3)*

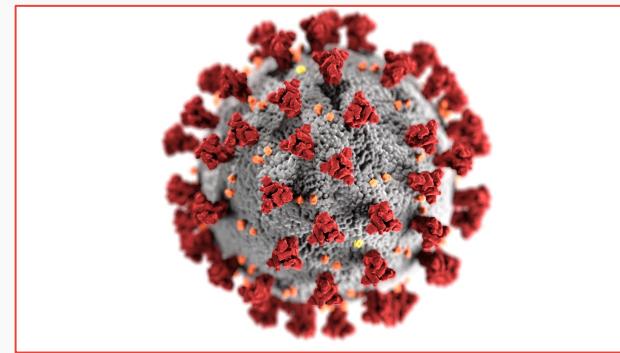


# How does ME/CFS relate to Long COVID?

Subset of people with Long COVID have **symptoms indistinguishable** from ME/CFS.

Some of these people still meet the **diagnostic criteria** for ME/CFS even at 1 year.

People with ME/CFS and a subset of Long COVID **share similar needs** and face essentially the same **barriers to care** regardless of proposed case definitions.



**COVID-19 could quickly double the prevalence of ME/CFS cases**

[Komaroff & Bateman \(2021\). Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?](#)

“

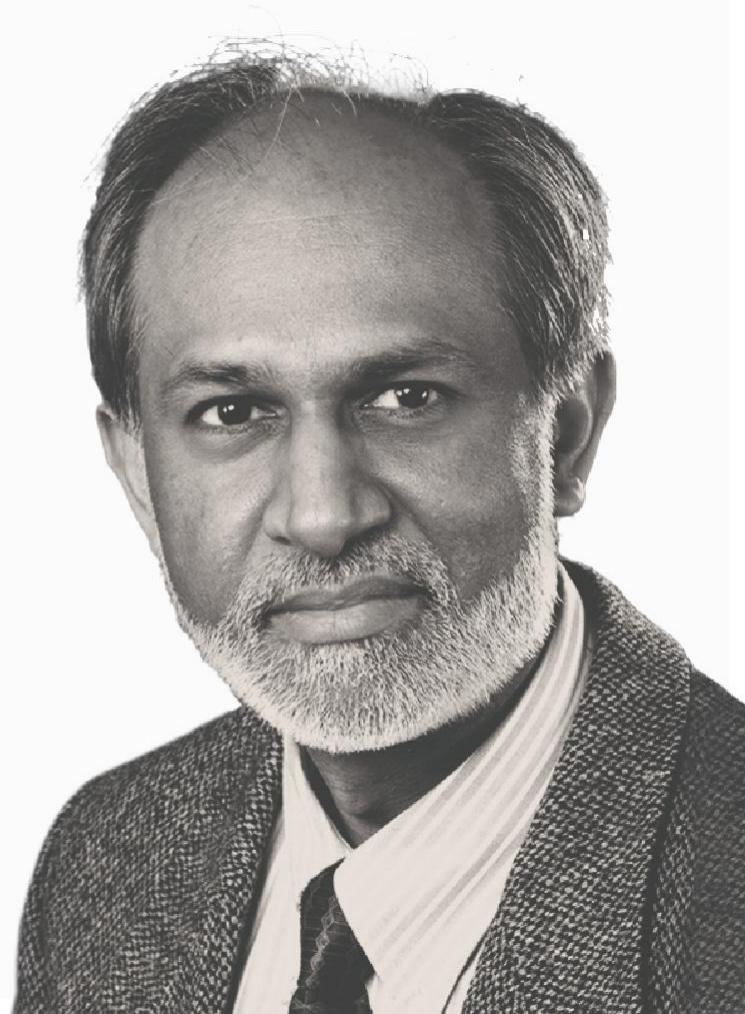
I think people—agencies, Congress, everybody—should be really focused [on the possibility that some COVID-19 patients will develop **ME/CFS**].

They really need to appropriate resources to quickly get into this field, get lots of people interested in studying these patients, and try to get to the bottom of it.”

— **DR. AVINDRA NATH**

INTRAMURAL CLINICAL DIRECTOR, NINDS, NIH  
DIRECTOR, TRANSLATIONAL NEUROSCIENCE CENTER, NINDS, NIH

Zimmer, K. "Could COVID-19 Trigger Chronic Disease in Some People?" *The Scientist Magazine* (July 17, 2020). <https://www.the-scientist.com/news-opinion/could-covid-19-trigger-chronic-disease-in-some-people-67749>



**I think [ME/CFS and Long Covid] overlap so much, that over time they will become one and the same.**

ME/CFS is thought in most cases to be a post- some infectious illness. Only difference here is that we know what virus is driving it in large numbers of persons.”

**— DR. WALTER KOROSHETZ**  
DIRECTOR OF NINDS, NATIONAL INSTITUTES OF HEALTH

*Trans-NIH ME/CFS Working Group Meeting February 25, 2021.*



“

**Post-viral illnesses are not new.  
The cracks in our system that  
Long COVID has exposed are not  
new. It's just that now more people  
are paying attention.**

We are counting on you... to address  
these issues head on... At this point  
there's no other option.”

— LISA MCCORKELL

LONG COVID PATIENT, ADVOCATE, RESEARCHER  
POLICY ANALYST, CA DEPT. OF SOCIAL SERVICES

*The Long Haul: Forging a Path through the Lingering Effects of COVID-19:  
Hearings before the Subcommittee on Health of the Committee on Energy  
and Commerce , 117th Cong. (2021) (testimony of Lisa McCorkell).*



# Recommendations for Additional Resources on ME/CFS

Centers for Disease Control and Prevention. Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Information for Healthcare Providers.  
Available from: <https://www.cdc.gov/me-cfs/healthcare-providers/index.html>

Institute of Medicine Report (2015), *Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Redefining an Illness:*  
<http://www.nationalacademies.org/hmd/Activities/Disease/DiagnosisMyalgicEncephalomyelitisChronicFatigueSyndrome.aspx>

ME/CFS Diagnosis and Management in Young People: A Primer (2017)  
<https://www.frontiersin.org/articles/10.3389/fped.2017.00121/full>

U.S. ME/CFS Clinician Coalition  
<https://mecfscliniciancoalition.org>

Pacing and Management Guide for ME/CFS  
[http://www.meaction.net/wp-content/uploads/2021/02/Pacing-and-Management-Guide-for-ME\\_CFS-9.pdf](http://www.meaction.net/wp-content/uploads/2021/02/Pacing-and-Management-Guide-for-ME_CFS-9.pdf)

Diagnosis and Management of ME  
<http://www.meaction.net/wp-content/uploads/2018/10/Diagnosis-and-Management-of-Myalgic-Encephalomyelitis-MEAction.pdf>

Falk Hvidberg M, Brinth LS, Olesen AV, Petersen KD, Ehlers L. (2015). The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). PLOS ONE 10(7): e0132421. <https://doi.org/10.1371/journal.pone.0132421>

Mirin, A., Dimmock, M., & Jason, L. (2020). Research update: The relation between ME/CFS disease burden and research funding in the USA. Work, 66(2), 277-282. <https://content.iospress.com/articles/work/wor203173>

Jen Brea's TED Talk: What happens when you have a disease doctors can't diagnose  
Video- [https://www.ted.com/talks/jennifer\\_brea\\_what\\_happens\\_when\\_you\\_have\\_a\\_disease\\_doctors\\_can\\_t\\_diagnose](https://www.ted.com/talks/jennifer_brea_what_happens_when_you_have_a_disease_doctors_can_t_diagnose)

# Recommendations for Additional Readings on Long COVID

2021 Will Long COVID Lead to ME/CFS?

<https://www.frontiersin.org/articles/10.3389/fmed.2020.606824/full>

2021 Confronting Our Next National Health Disaster - Long-Haul COVID

<https://www.nejm.org/doi/full/10.1056/NEJMp2109285>

2020 Body Politic. What Does COVID-19 Recovery Actually Look Like? An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team.

<https://www.wearebodypolitic.com/bodytype/2020/6/3/covid-19-support-group-survey-results>

2020 Long Haulers Are Redefining COVID-19

<https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/>

2020 Post-Viral Syndrome and ME/CFS: What Every Clinician Needs to Know (CME)

Video -[https://ceitraining.org/courses/course\\_detail.cfm?mediaID=872#.YR2IoS2cYy8](https://ceitraining.org/courses/course_detail.cfm?mediaID=872#.YR2IoS2cYy8)

2020 US ME/CFS Clinician Coalition Letter: Post-COVID “Long Haulers” and ME/CFS

[https://drive.google.com/file/d/15Z1pPMsTvxKe\\_eJtNG3XyXNxx9gB2xxU/view](https://drive.google.com/file/d/15Z1pPMsTvxKe_eJtNG3XyXNxx9gB2xxU/view)