DEALING WITH POST COVID SYMPTOMS, From The Perspective of a Long Hauler

Written by u/BestKittens, First Wave Long Hauler located in the US 📅 **Last edited: March 6, 2025**

Note: Next week-ish I will post a revised document here that has the same information in a better format. Thanks!

FYI: This guide is free, unaffiliated, and always will be. It's my way to give back to the communities that helped me.

Voice Accessibility: You can set up your phone or computer to read this document to you. There are accessibility features on computers and smart phones to help you.

> **iPhone:** Go to Settings—> Accessibility—>Spoken Content. Turn on **Speak Selection** and **Speak Screen**. There is also a control for the **Speaking Rate** to slow it down.
>
> **Android** has very similar Accessibility features with **Select to Speak, TalkBack,** and **Voice Access.**

Why This Guide Exists

I created this guide with the **information I wish I'd had** at the start of my illness—insights that could have helped me feel **less alone** and given me **both palliative and interventional options** to explore.

You'll find links to resources, studies, expert interviews, as well as practical at-home strategies for Long COVID, which also applies to many infection based complex chronic illnesses.

This information is meant for **anyone dealing with post-viral symptoms** or Post Acute Sequelae Covid (PASC), including:

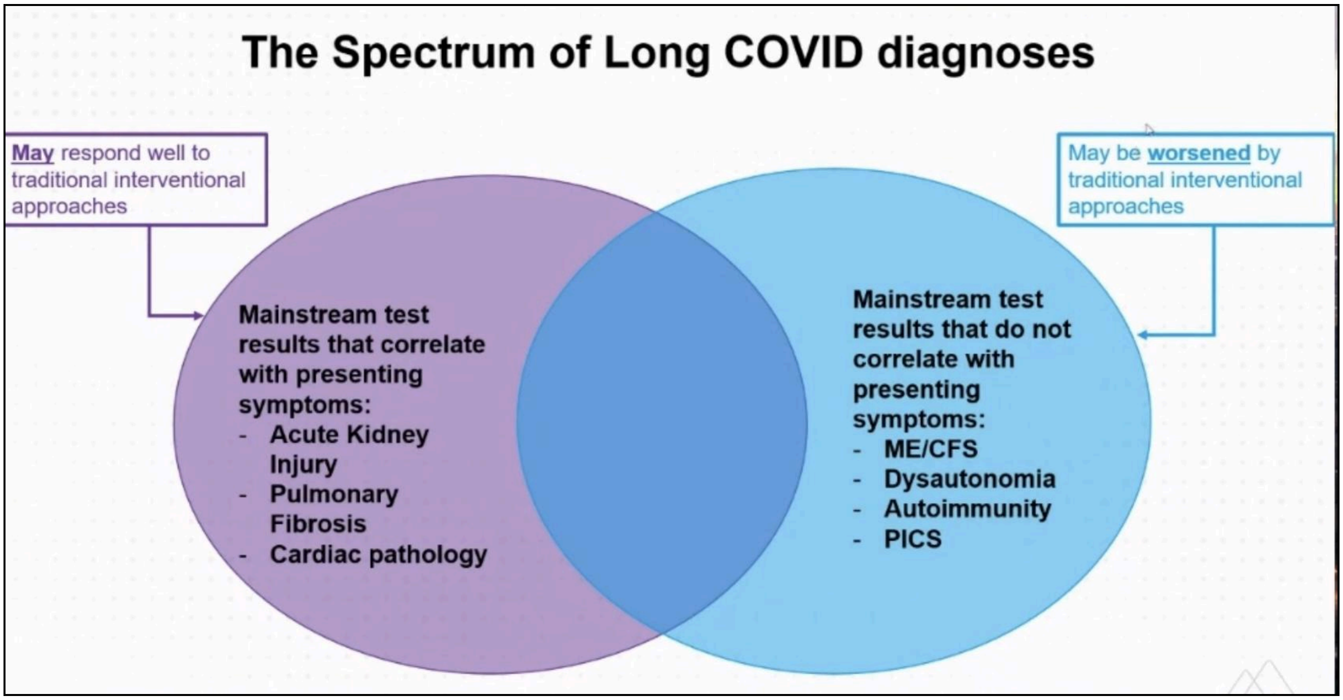
- Those who are **currently sick** with a COVID infection.
- Those who have **recently recovered** and want to prevent long-term issues.

- Those in the **early, overwhelming days of Long COVID**—whether from one or multiple infections or vaccine injury.
- Those, including **children and young people**, that are experiencing fatigue and other symptoms.
- Those that are **struggling to find treatment** or medical care.
- For those with **long-term post-infection issues** seeking new approaches, insights, or perspectives.

⚠️ Disclaimer

The information in this document is **for informational purposes only** and is **not a substitute for medical advice**. Always consult a **qualified healthcare professional** for symptom management. Your doctor should order **blood work, tests, and imaging** to address underlying vitamin deficiencies, known conditions, disease, and damage.

📖 **For guidance on navigating the medical system**, see **"Seeking Medical Care"** at the end of this document.



The Spectrum of Long COVID diagnoses

May respond well to traditional interventional approaches

Mainstream test results that correlate with presenting symptoms:
- Acute Kidney Injury
- Pulmonary Fibrosis
- Cardiac pathology

May be **worsened** by traditional interventional approaches

Mainstream test results that do not correlate with presenting symptoms:
- ME/CFS
- Dysautonomia
- Autoimmunity
- PICS

From The Pathobiology of Long Covid, from Long Covid Rehabilitation by CoRE at Mount Sinai

TOPICS

This document provides a comprehensive guide to understanding and managing Long Covid, covering its onset, common symptoms, and effective strategies for treatment and daily life.

It addresses key challenges such as fatigue, brain fog, gut dysbiosis, heart palpitations, MCAS, and mold toxicity, offering insights into supportive treatments and lifestyle adjustments. Resources and tips for both children and adults.

Practical advice includes energy management, improving sleep quality, leveraging technology, and recognizing warning signs of crashes. Additionally, it explores options for seeking medical care, finding supportive resources, and enlisting help from loved ones or professionals.

The guide also highlights ways to avoid viral infections and maintain overall wellness through diet, hydration, and antiviral foods

To Access The Dynamic Document Outline (Links):

- Computer: Click “Show Tabs and Outline” icon on the upper left corner of the rulers of this document page. The outline will appear to the left of the document
- Phone: 1. Tap the ⋮ icon at the top-right corner of the app/screen. 2. Tap "Document outline". The outline will appear at the bottom of the document.
- Once the outline is visible, click any topic to go directly to that section.

Making This Guide More Accessible

Brain fog is real, so I’ve structured this guide to be **easier to read and navigate:**

✅ **Wider spacing and breaks** to improve readability.

✅ **Videos and Podcasts** for those that find listening easier than reading.

✅ **Direct links** throughout the text and in the **Resources** section.

✅ Links are **blue** and marked with icons for easy identification:

📝 **Read** 🎧 **Listen** 📹 **Watch** 📱 **App** 💊 **Supplements + Medications**

NOTE: If you find a broken link, please message me on Reddit at u/BestKittens.

COST: I’ve made an effort to include as many **accessible symptom management options** as possible. However, some referenced treatments and lifestyle change recommendations **can be costly**. While I recognize this isn’t feasible for everyone, I feel it’s important to include **everything that could potentially help** so that you can explore what’s right for you in your specific situation.

ACUTE INFECTIONS and TRYING TO AVOID LONG COVID

If you find yourself with a current or recent infection, see 📝 “Acute Infections + Trying to Avoid Long Covid” for resources and tips.

Viruses spread easily in indoor and crowded environments, making it challenging to avoid exposure. While no strategy is foolproof, taking steps to reduce the risk of infection can help protect your long-term health.

How can you prevent Long Covid? While there’s no guaranteed way to eliminate risk, minimizing any opportunity for exposure to Covid infections is the most effective approach. Wearing a well-fitted respirator such as an N95 or P100 in shared air spaces significantly reduces any chance of transmission.

- Why Are People Wearing Masks in 2025? a mental health professional’s perspective

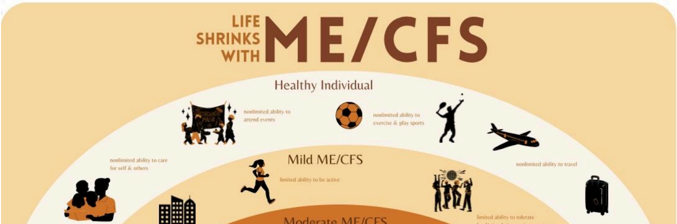
See Taking Precautions and Avoiding Viral Infections at the end of this document for more information on how to protect yourself and others.

Still, there are few safe air spaces or people taking precautions, making it all too easy to get infected. Recovery from any infection takes time.

Long Covid is typically considered when symptoms persist for 3–6 months beyond the acute phase. Still, I’m of the mind that one should proceed as if they do have Long Covid, by resting, eating healthily, and avoiding stress in hope of full recovery.

MY EXPERIENCE + PERSPECTIVE

In brief, I am an ME/CFS, Dysautonomia and Histamine Intolerant type Long Hauler. At my



worst I was mildly severe, bedbound and housebound. Despite the odds of recovery, I have seen improvement year over year and I am now more hopeful than ever because I meet the definition of Mild ME/CFS and dare to hope for recovery 📝 (Myalgic Encephalomyelitis or ME/CFS Association Symptom Scale).

Right: u/hazelemons made this Severity Scale that very effectively illustrates disease severity.

You can read more about my personal experience here: 📝 2020 - 2025 My Illness, Diagnosis and Hopeful Road to Recovery, which also includes my current daily and weekly wellness practices, and 📝 💊 Medication And Supplement Regimen that have helped me improve.

The long and short of it is that I've made progress by:

- Participating in an LDN/LDA study at Stanford
- Learning how to pace, rest deeply and increase rest during symptom crashes and flares,
- Increasing the frequency and amount of daily wellness practices,
- Participating in the RECOVER Paxlovid trial through UCSF,
- Increasing the supplements I'm taking to address mitochondrial and vascular function. Oxaloacetate is particularly helpful.
- Daily wellness exercises to promote a calm nervous system, strengthen your body's stress responses and stimulate your vagus nerve. My practice includes 2-3 largely free or low cost activities per day depending on symptom weight: yoga Nidra meditations (the longer the better), lying on my acupressure mat with an eye mask, 432 hz sound therapy, humming, cold showers, teas, scent therapy and warm or cool compresses, quiet time in the sun / garden and crocheting.
- Treatments such as acupuncture and NIR light therapy. The former is gentle and supportive, while the latter has helped significantly with my energy and brain fog.

I’ve been very lucky to be able to rest, get to institutions to participate in studies, to afford the things I’ve tried, and that my body has been, albeit very slowly, healing over time.

Even without that luck, there are very accessible things that have made a real difference for me and my body that I’ve included all of it in this document.

ONSET OF LONG COVID

Sadly, we can do everything right and still get Long Covid. Even if you didn’t do everything right, and maybe you followed your doctor’s advice to return to work and exercise, or maybe a vaccine caused your symptoms… Whatever the case, Long Covid is not your fault. Repeat that. It is not your fault.

- 📹 What Is Long Covid? The Long Covid Physio
- 📹 Pathogen Persistence, CoRE at Mount Sinai with Dr’s Amy Proal and David Putrino

Our Public Health institutions, our governments on a local, national and worldwide level failed us and continue to fail us by pushing a return to normal that benefits profits over people.

Still, there are trusted institutions and doctors working tirelessly trying to find biomarkers and treatments through research and practice.

Mount Sinai and its CoRE program is the gold standard for clinical care, funded by POLYBIO that’s doing important work. The following links will take you to two series, one geared towards helping patients understand Long Covid and other post-viral illness, and the other geared towards helping practitioners understand how to care for patients with Long Covid.

- 📹 CoRE Knowledge Sessions at Mount Sinai (for patients)
- 📹 Long Covid Rehabilitation, CoRE at Mount Sinai (for practitioners)

I highly recommend you and/or your loved ones watch or listen to these. You will walk away with a deeper understanding of Long Covid and its impacts and dysfunctions as clearly articulated by leaders in the field.

- Do wait for a time you have the bandwidth,
- You can always ask AI, such as Chat GPT or Gemini, to TLDR the transcripts, which are usually available in the Video Description.
- You can also slow down the speed and volume of the video so it's not as overwhelming to listen to.

These are the individuals and resources I trust and follow:

- Dr. Zayid Al-Aly, Clinical Epidemiology Center, and Chief of the Research and Education Service at the VA Saint Louis Health Care System
- Dr. Ron Davis, Professor of Biochemistry and Genetics Stanford University
- Dr. Wes Ely, Internist, Vanderbilt University
- Dr. Akiko Iwasaki, Iwasaki Lab, Sterling Professor of Immunobiology and Molecular, Cellular, and Developmental Biology at Yale University
- Dr. David Kaufman, Internal Medicine physician at the Center for Complex Diseases
- Dr. Amy Proal, President/CEO of Polybio Research Foundation
- Dr. David Putrino, Director of Rehabilitation Innovation for the Mount Sinai Health System
- Dr. Ilene Ruhoy, Neurologist and an Environmental Toxicologist at the Center for Complex Diseases
- Dr. David Tuller, Senior Fellow in Public Health and Journalism, Center for Global Public Health, UC Berkeley
- 📝 CITIZENS COVID COALITION
- 📝 MEAction
- 📝 Mount Sinai Center for Post Covid Care
- 📝 Polybio Research Foundation

- 🎧 Raise the Line Podcast
- 📹 RTHM Health
- 📹 The Long Covid Clinic, What You Can Do
- 📹 Unraveled: Understanding Complex Illness
- 📹 Gez Medinger on YouTube
- 📹 Long Covid Physio on YouTube
- 📝 Virology Blog
- 📝 Yale School of Medicine Long Covid

Anyone can get Long COVID, regardless of age or health and can develop after even one asymptotic infection.

The same is true of PAIS's (Post Acute Infection Syndromes) and Vaccine Injuries.

It has been found in studies that your chances of negative outcomes increase to 40% after a third Covid infection.

As I'm sure you realize, the risks are dire with Long Covid which has shone the light on other post viral chronic complex illness.

- 📹 The Impact of Long Covid on Daily Life, The Long Covid Physio

Many of us continue today to get bad advice from our doctors, many of whom scoff at the idea of PAIS, and particularly the dangers associated with Covid articulated in thousands of studies. They encourage exercise above all else, dismiss our symptoms as anxiety, hysteria and hypochondria, or dismiss us due to their own biases, internalized or otherwise, especially against women, POC, LGBTQIA and young folks.

- Chronic diseases misdiagnosed as psychosomatic can lead to long term damage to physical and mental wellbeing, study finds Peer-Reviewed Publication UNIVERSITY OF CAMBRIDGE

These YouTube series playlists highlight the standard of care *every one of us* should be getting.

- 📹 Long Covid Rehabilitation, CoRE Symposium for Practitioners May 2024
- 📹 Unraveled: Understanding Complex Illness with Dr's Kaufman and Ruhoy
- 📹PAIS (Post Acute Infection Syndromes: Root Causes, Drivers and Actionable Solutions, CoRE Podcast
- 🎧 Raise the Line Podcast

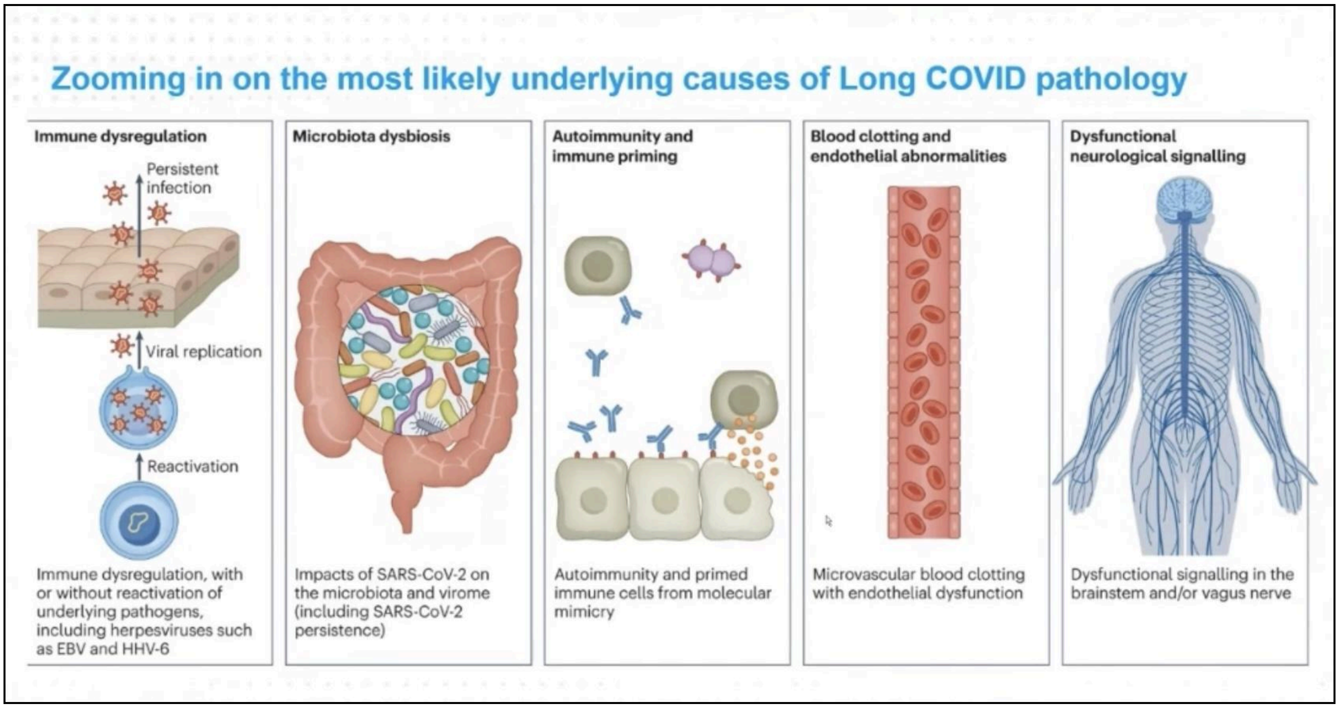
These doctors and organizations give me some hope that the larger medical community will someday catch up. In the meantime, sadly many of us are left disabled, house or bed bound, without treatment and vulnerable to losing our relationships, homes and livelihoods.

- 'We shall have spring again' - Messages of hope and solidarity for 2025
    - "My best hope is that these heartwarming messages about scientific progress and collaborative endeavour encourage you at some level, whatever (and maybe even despite) your circumstances, especially as we enter a new year."

This document seeks to fill the gap in care I experienced, to give you a roadmap from the perspective of a Long Hauler to do what you can at home, to try to understand what's happening in your body and to get the most you can from your doctors. That's a lofty goal. But why not try?

- 📹 Dr. David Putrino on the findings from the new Nature study of Long Covid Immune profiling, on David M Tuller
    - Both Dr. Putrini and Dr. Tuller are well respected in the Long Covid community. The above video contains an excellent discussion between these two doctors regarding medical gaslighting, the failings of the system, and the presumption that Long Covid and its associated symptoms are indicative of psychological issues.
    - 📝 Distinguishing features of long COVID identified through immune profiling, Nature September 2023

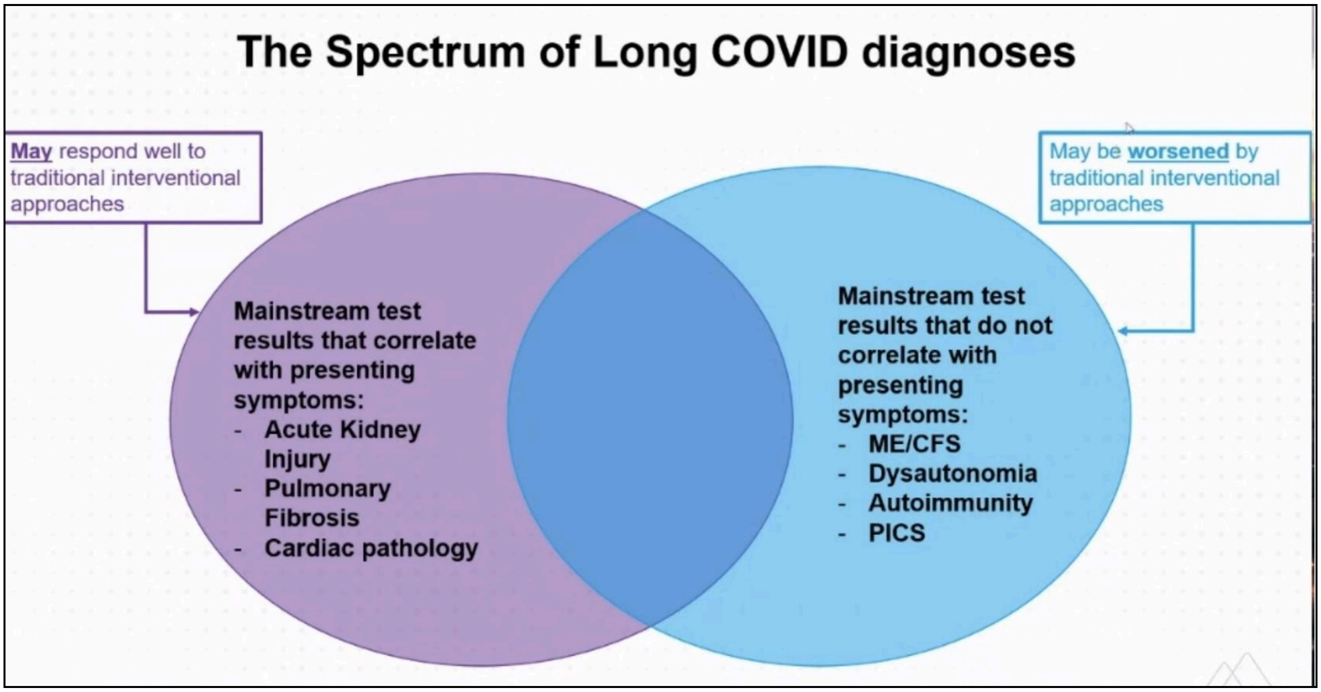
PERSISTENT SYMPTOMS



From [The Pathobiology of Long Covid, from Long Covid Rehabilitation by CoRE at Mount Sinai]

If you're experiencing persistent symptoms and suspect or even know you have Long Covid, I encourage you to take things very slowly and step by step.

- This is a complex illness. It can involve one or more of the above underlying causes.
- Breaking lifestyle adjustments and finding treatments down into small steps will be less emotionally overwhelming.
- Try things one at a time to make sure that what you're doing or taking is adding to your symptom burden.
- It's important to seek medical attention to rule out or diagnose damage and disease that is understood by our medical community.



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Mainstream test results that correlate with presenting symptoms:
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- **PICS**

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APPROACHES TO TRY ON YOUR OWN

To date, there is no cure or treatment for Long Covid and sadly research is frustratingly slow. That said, we are learning more and more every day, there are symptom management strategies. What's more, there are things you can do now such as,

- Deeply rest and use Pacing techniques
- Make as many lifestyle modifications as possible
- Find Community, including those that have dealt with chronic illness without treatment or respect for decades
- Explore the possibilities of mitochondrial, vascular dysfunctions and histamine intolerances
- Try over the counter medications and supplements
- Try off-label and low dose medications
- Address Diet and Gut Dysbiosis
- Create a daily wellness practice
- Avoid further infections

It's true that everyone's experience with these conditions is unique, and what helps one person might not help another. Some individuals experience very severe symptoms, which can be incredibly challenging. That's why **it's so important to explore strategies and find what works best for you**, especially if you're experiencing fatigue. **Taking proactive steps can make a real difference**.

FATIGUE

The most common symptom of Long Covid is fatigue. Dr. David Putrino at CoRE at Mount Sinai said that 80% of Long Haulers experience fatigue.

Many conditions commonly associated with Long Covid, such as ME/CFS, Dysautonomia, POTS, Sleep Apnea, MCAS and Histamine Intolerance among many others, can present as fatigue.

Each of these sources of fatigue have a different management approach.

- 📹 Is It MCAS, Dysautonomia or Both?, Gez Medinger
- 🎧 What Clinicians Can Learn About Managing Uncertainty, Raise the Line

Some of these approaches are directly incompatible with the others. For example, folks with POTS might find relief with exercise, while exercise can be incredibly dangerous for someone with ME/CFS.

If you're experiencing fatigue, it's important to take things slowly, step by step and take notes so that you can try to understand what is happening by looking at what helps alleviate and what exacerbates your symptoms.

- 📱 Visible: Pacing for Illness is a great app for tracking your symptoms and, with their armband, managing pacing and heart rate.

- 📝 Trial By Error: Trudie Chalder Is Co-Author on Another Bad Exercise Paper, David Tuller, DrPH February 2025

It will take time to figure out the source, or possibly multiple sources contributing to your fatigue and how to manage each in context of all of your diagnoses.

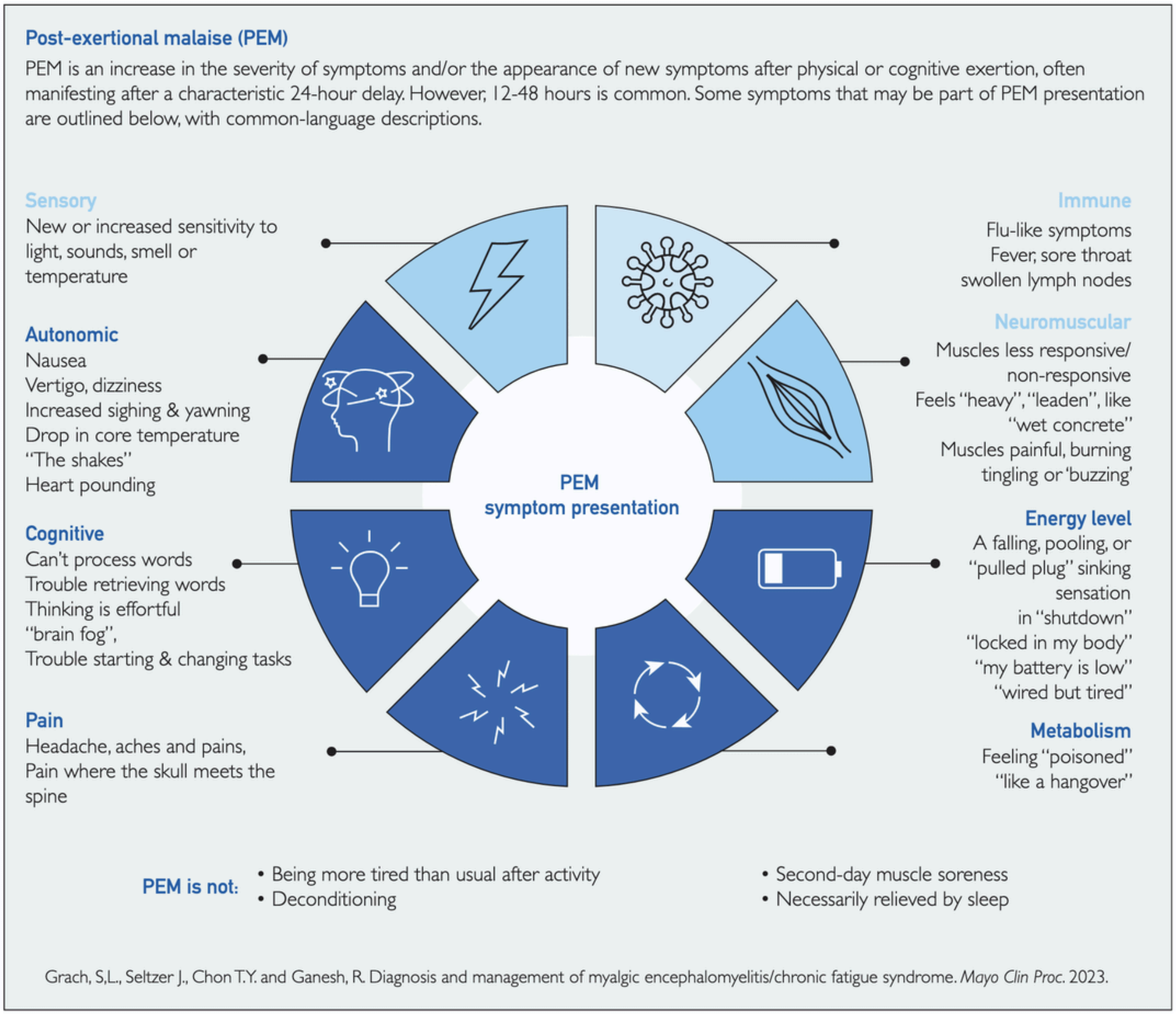
Identifying symptoms and triggers, and making changes based on those discoveries, can help alleviate the intensity of one or hopefully more symptoms.

Addressing your symptoms involves learning how to pace effectively, how to rest deeply, improving your specific diet needs and biome health, creating good sleep hygiene, starting off-label or over the counter medications, vitamins and supplements to address deficiencies and supporting your mitochondrial and vascular function, as well as calming your nervous system with wellness practices.

Each of these things alone may only offer a bit of improvement. As frustrating as that might be, if you make 10 or 20 of these small improvements they will add up to make a bigger difference in your quality of life.

Studies consistently show (through each variant) that 10% of people develop Long Covid after an infection. From there 50% of those develop ME/ CFS. With multiple infections, those odds go up with each time. This is why it's important to focus on radical rest and stop exercising until you are certain you don't have ME/CFS.

- 📝 The CDC's information on ME/CFS diagnostic criteria.
- 📝 Subreddit r/CFS has more information on their pinned post for new members.



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.

PEM symptom presentation

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

Grach, S,L., Seltzer J., Chon T.Y. and Ganesh, R. Diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome. *Mayo Clin Proc.* 2023.

The hallmark symptom required for an ME/CFS diagnosis is Post Exertional Malaise or PEM, the worsening or crashing of symptoms 1-3 days after exertion.

PEM is difficult to pin down, because in early days of Mild illness, the fatigue may only appear once every few weeks and isn't easily correlated with any particular physical, emotional or intellectual effort.

That was the case for me in the beginning and I kept pushing at the encouragement of my doctors, landing me at a Mildly Severe level of disability.

For those that are experiencing more intense fatigue, it can be equally difficult to pin down because you may be in what is considered a rolling crash, an unrelenting period of fatigue that lasts weeks, months or even years. Even more confusing is that you can experience a worsening of symptoms within the rolling crash. At this point, you have so little energy, that the simplest of movements, exposure to the environment or short conversations can lead to a crash within a crash.

This happened to me after a year of pushing through occasional bouts of fatigue, they became longer and longer, more and more intense as time went on until the fatigue was unrelenting and I was forced to go on disability. Throughout, my doctor's *still* encouraged me to exercise.

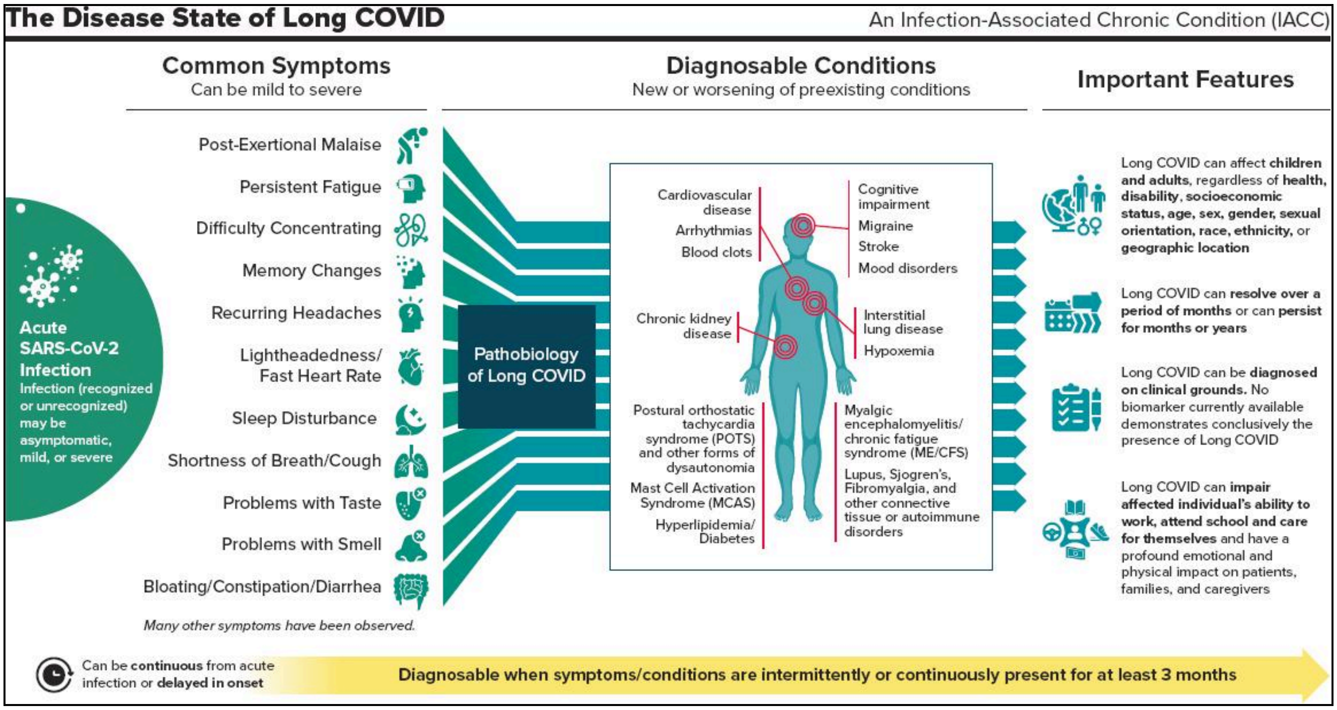
- 📹 Muscle Abnormalities Worsen in PEM
- 📖 Cerebrospinal fluid metabolomics, lipidomics and serine pathway dysfunction in myalgic encephalomyelitis/chronic fatigue syndroome (ME/CFS) March 2025

Whichever level of fatigue you are experiencing now, stop pushing through your symptoms and engage in aggressive, deep rest and careful pacing. This is the most important thing you can do for yourself now.

See TREATING SYMPTOMS in the next section for more information and resources on Calming The Nervous System, Managing Your Energy, Warning Signs and Crashes, Technological Help and Lifestyle Adjustments to Deal With Fatigue.

Please note that it is important to avoid stimulants in dealing with your fatigue. Stimulants such as caffeine and well known uppers, legal or otherwise, can give you a "false" energy that leads you to believe that you can do more. This will lead to a severe crash given the "false" energy is masking your actual symptoms. If you're experiencing MCAS or HI, caffeine may cause exacerbated symptoms.

TREATING SYMPTOMS



Long COVID can affect **children and adults**, regardless of **health, disability, socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity,** or **geographic location**

Long COVID can **resolve over a period of months** or can **persist for months or years**

Long COVID can be **diagnosed on clinical grounds.** No biomarker currently available demonstrates conclusively the presence of Long COVID

Long COVID can **impair affected individual's ability to work, attend school and care for themselves** and have a profound emotional and physical impact on patients, families, and caregivers

📝 From [Long Covid: Major Findings and Mechanisms and Recommendations]

- 📹 Long Covid Treatment Explained: A Comprehensive Patient Guide, UT Health Austin
- 📝 Long COVID Essentials: New resources published, December 2025, including resources for young people
- 📝 Long-Term Health Effects of COVID-19: Disability and Function Following SARS-CoV-2 Infection 2024

It's important to engage the medical community to undergo testing for vitamin deficiencies, organ damage, autoimmune disease, and address anything diagnosed by your doctor. See "Seeking Medical Care" toward the bottom of this document for more advice on how to navigate asking for this.

- Sometimes abnormal test results are found, and if there's treatment available solving one mystery can lead to some level of improvement.

- Often test results come in as “normal”, which can be quite frustrating when you’re looking for answers for the serious symptoms you’re experiencing.
- There are Long Haulers that have recovered or gone into remission or recovery by healing over time.
- Others in the long hauler communities have found treatments and practices that do help their symptom severity and improve their lifestyles.

There are now many medications and supplements that some Long Haulers have found helpful for you to try,

- 📝 Using existing medications off-label from The Sick Times x Long COVID Justice
- 📝 Supplements & Over-The-Counter Treatments That May Help With Long Covid from The Sick Times X Long Covid Justice
- 📹. Long Covid Treatments: Go-To, Promising and Experimental Options, March 31, 2025
- 📹. Long COVID and supplements — Bateman Horne Center
- 📹. Dietary supplements in the time of COVID-19 – National Institutes of Health (NIH)

While Long Covid symptoms are varied, Autonomic, Vascular and Mitochondrial Dysfunctions have been found to be incredibly common.

- ▶ The Latest Research on Mitochondrial Dysfunction in Long Covid & ME/CFS | With Prof. …
- 📹 PAIS (Post Acute Infection Syndrome) Podcast Ep 4: Mechanisms of Downstream Pathology Part 1 and Part 2 on YouTube

Given this, prioritize rest and pacing alongside meds and try supplements that support mitochondrial function, lower inflammation, reduce microclots and improve neurological function.

AT HOME TREATMENTS

Thankfully, there are ways you can help yourself:

- Start with deep rest, wellness activities and a richly nutritious diet
- Explore lifestyle adjustments that can help conserve the energy you do have
- Consider 💊 common medications and supplements when you feel it is appropriate for you.
- Explore 💊 Using existing medications off-label for Long COVID
- Beyond Antivirals: Alternative Therapies for Long COVID, Nov 2024 NIH

Long Covid bodies are sensitive. When trying anything new, whether a wellness activity/treatment, medication or supplement, it's very important to be both careful and cautious.

- Approach things low and slow and watch for symptom exacerbation.
- Try one thing at a time, especially for new meds/supplements or anything that involves increasing your heart rate such as movement, hot showers or infrared light therapy.
- Find and engage a doctor to find vitamin deficiencies, order blood work and rule out major damage and disease.

Some foundational practices important for managing any symptoms include,

- Proper Hydration. Drink enough water and use Electrolytes to hold onto that water.
- Compression socks improve circulation and can help relieve mild pain. Use compression while you're up and about. Using them while laying down can create issues when using them for medical purposes. Consult your doctor
- If you have POTS, compression garments and sodium (not salt) may help alleviate some of your symptoms. Consult your doctor and visit both 📝 Dysautonomia International, For Patients and 📝 Dysautonomia International, Postural Orthostatic Tachycardia Syndrome for more information.
- No sugar. No alcohol. No processed foods. These cause increased inflammation and will exacerbate all sorts of symptoms.

You will need to go through a process of trial and error to find the things that work for you and that do not exacerbate any of your symptoms.

Be an observer of your condition and what you engage in or take. Try things one at a time, and keep careful notes.

If you notice something is exacerbating your symptoms, stop and evaluate. Learn about the thing you are doing and any possible interactions or side effects. Reflect on what's happening …

- Am I too severe for this right now?
- Is this dangerous for me to continue?
- Is this a herx reaction?

If you don't notice negative or positive effects, reflect on whether this is something that needs time to develop and heal. Continue if you feel it has potential, and discontinue if it doesn't feel right for you.

If you are experiencing PEM, LDN can be helpful for roughly 60% of people.

Oxaloacetate supplementation, a natural compound involved in the cellular energy process that has been found to be very low in folks with ME/CFS, can be even more so. In both cases, start at the lowest dose possible and increase weekly for LDN and roughly every few days for Oxaloacetate.

- 💊 Ageless Rx
- 💊 Healthspan
- 💊 Oxaloacetate CFS 500 mg bottle
- 💊 Benegene Oxaloacetate 100 mg bottle

Note: The above Oxaloacetate are proprietary products; the cheaper bottle available on Amazon is not the same thing that has been studied showing fatigue improvement. Note that both sellers offer a full refund of the first bottle if it doesn't work for you.

For LDN, start at the lowest dose possible and do not increase if you're having adverse effects. If you are, lower your dose to where you were having benefits without symptoms. Some people do well on .5 mg and others 8 mg. See r/lowdosenaltrexone.

- Low-Dose naltrexone restored TRPM3 ion channel function in natural killer cells from long COVID patients

For Oxaloacetate, take on an empty stomach if tolerated, otherwise with breakfast. Titrate every few days until you find the dose that you feel energized. Note that you may feel a sluggishness until you find the right dose.

- 📝 28 Days on Oxaloacetate
- 📝 A Reddit comment regarding a cheaper and possibly effective alternative to Oxaloacetate.
- 📝 RESTORE ME? Oxaloacetate Scores in Randomized Controlled ME/CFS Trial, Dec 2024 Health Rising
- 📝 RESTORE ME: a RCT of oxaloacetate for improving fatigue in patients with myalgic encephalomyelitis/chronic fatigue syndrome November 2024
- 📝 SARS-CoV-2 can cause lasting damage to cells' energy production August 2023

CALMING THE NERVOUS SYSTEM

Deep rest can be particularly difficult when dealing with illness that causes sleep disturbances.

Calming the nervous system, stimulating the vagus nerve and promoting deep rest are important in the healing process. Recognizing and removing ourselves from toxic and stressful situations and people can also be very helpful in calming the fight or flight our nervous system is in.

Wellness activities are not going to cure you, but they can help calm your autonomic nervous system that has been damaged, help you manage stress that exacerbates symptoms, and provide an opportunity for deep rest other than sleep which is especially important if you're experiencing sleep disruption. Many wellness activities are correlated with Immune System health.

- 📹 Autonomic Dysfunction, CoRE at Mount Sinai
- 📹 Mitochondrial Dysfunction, CoRE at Mount Sinai
- 📹 Sleep (Per Chance to Dream), Unraveled : Understanding Complex Illness

Covid damages our nervous system and causes our bodies to remain in a state of fight of flight that can increase anxiety and cause severe insomnia. Wellness activities can help stimulate your vagus nerve and calm your nervous system down from this agitated state. My favorites include,

- Humming to calm the vagus nerve
- Sound therapy such as Binaural Beats or 432 hz to lower stress responses
- Vagus Nerve Stimulation
- Yoga Nidra meditations up to a few times a day, preferably with noise-cancelling headphones. Look for Ally Boothroyd and Sahara Rose on YouTube.
- Guided meditation (I like Belleruth Naperstek)
- Acupressure mat time to improve circulation
- Cold showers.
    - I find a hot shower then cold while deeply box breathing and seated to help my sleep and energy.
    - Be careful if you are experiencing temperature dysregulation.

    - Start very slowly, 30 seconds at most, and stay seated.
    - Discontinue if it exacerbates your symptoms.
- Acupuncture, talk to your practitioner about gentle treatments
- NIR / FAR light therapy to heal damaged mitochondria

Resting is not as straight forward as you think. To truly rest, to rest deeply, involves relaxing the body and quieting the mind.

See SLEEP DISTURBANCE for tips and resources for day and night time rest,

SUPPORTIVE TREATMENTS

There are supportive and sometimes effective treatments available at a cost that calm the nervous system and support your body and its processes through manual therapies, nutrient and wellness therapies. I use qualifying statements because many don't respond or have negative reactions to one or more of these therapies even if they can afford them.

- Acupuncture
- Manual physical therapy
- Massage

Ask practitioners to be gentle in their treatment of you given your body's sensitivity.

Other available therapies that you can find at spas, chiropractor, offices, and anti-aging or longevity clinics include,

- Nutrient injections and IV drips
- NIR/FAR light therapy

Start slowly, particularly with NIR therapy, as it involves heat and can exacerbate heat intolerance symptoms if you start with a long session. Also make sure you're hydrated, and do something to increase circulation the same day; this can be light movement if tolerated, or time on an acupressure mat if movement isn't tolerated.

Search the r/covidlonghaulers subreddit for experiences and more information on these treatments and more.

My Experience

I've personally experienced these therapies mentioned. My current wellness routine includes weekly acupuncture and light therapy, alongside bi-weekly nutrient injections, which are particularly important given my plant-based diet.

I find weekly acupuncture, when tailored to my fatigue levels with gentle treatment, to be highly beneficial for calming my nervous system, promoting restful sleep, and supporting hormone balance.

Initially, I tried a FAR light therapy blanket at home but found it ineffective. Seeking a more comprehensive approach, I began using a NIR/FAR light therapy bed at a local clinic. This has yielded significant improvements in my sleep and a reduction in my resting heart and respiratory rates, as monitored by my Oura ring. My primary aim was to enhance energy levels and mitochondrial function, and I started observing positive changes around the 10th session.

Remarkably, a few days after my 9th session, I experienced a substantial boost in energy and cognitive clarity. I felt absolutely fantastic! Now, with over 16 sessions completed, I consistently enjoy good days, punctuated by four truly exceptional ones. To maintain these benefits, I've invested in a Healix Glow Pod blanket (which includes both NIR/FAR light and offers a chronic illness discount) for daily home use. I plan to continue my twice-weekly full-body bed sessions

> at the clinic for their intensive, head-to-toe coverage, while using the blanket for supplemental therapy on the other five mornings.
>
> In addition, I experienced frozen shoulder and endured four months of traditional physical therapy, which proved fatiguing. Seeking a more effective approach, I found a physical therapist specializing in manual therapy. This therapist provided deep massage and stretching techniques during in-clinic sessions and assigned passive stretching exercises for home practice between appointments. This approach was highly effective and, importantly, did not exacerbate my fatigue.

There are other types of treatments Long Haulers have had success with that aren't widely available, are cost prohibitive or only worked for a small number of who could afford them. Some of these are tied to promising research but are stuck in the red tape of bureaucracy.

- Search r/covidlonghaulers for more information and research.
- Stellate Ganglion Blocks or SGB
- Hyperbaric Oxygen Therapy or HBOT
- Peptides. See r/peptides (note people in this community are not chronically ill; be very cautious with their advice)
- Vitamin and antioxidant injections and IV drips, daily, weekly or biweekly

MANAGING YOUR ENERGY

Doing less can help you save your energy for the most important things, though radical rest is required for those experiencing deep or severe fatigue, particularly if it is unrelenting.

- 📹 The Impact of Long Covid on Daily Life, The Long Covid Physio
- 📹 Pacing, The Long Covid Physio

- 📹 Exercise, The Long Covid Physio
- 📝 Avoiding The Crash, Living With a Chronic Illness, The Bateman Horne Center
- 📝 Aggressive Rest Therapy (ART) and Aggressive Resting, from ME and More
- 📹 The When and How of Pacing: Why Pacing Works and How to Do It (Better), Gez Medinger
- 📹 Pacing, Pushing and PEM: The Balance Between Rest, PEM and Autonomic Conditioning Part 1, Gez Medinger
- 📹 Q&A Pacing, Pushing and PEM: The Balance Between Rest, PEM and Autonomic Conditioning Part 2 , Gez Medinger
- Do You Ever Just Say “Fuck It” and Do More? r/cfs

The idea is to stay at your baseline, the level of activity that you can maintain without worsening your symptoms.

This is sometimes referred to as your “energy envelope” or “spoons”. Both refer to the amount of energy you have to spend.

- “I don’t have any spoons to waste on xyz activity that I don’t care about.”
- “I have to go to a doctor’s appointment today, which will take all of my energy. Cooking in addition to that is way outside of my energy envelope so I’ll have to order in today.”

Your goal is to never push beyond your energy stores/spoons/envelope because that will result in a crash, which is an intense exacerbation of your symptoms. Any time you are experiencing a crash, your body isn’t able to focus on healing.

Experimentation and daily note taking can help you discover your limits, triggers and even warning signs that you’re about to go too far thus helping you prevent crashes and allow your body to heal.

Your triggers are those things, specific to you, that you know will lead to a crash. These can be any activity, food, drink, environmental factorSome possibilities,

- Bright lights or too much sunlight
- Sitting in a loud mall
- Watching an action movie
- A conversation or spending time with an exhausting person
- A single or group of food or drink
- Certain self care or cleaning products
- A storm or a change in weather.
- Mold
- Too much screen or video game time
- Paying bills or reading a technical document

WARNING SIGNS and CRASHES

While Triggers cause crashes, you may discover that your body gives you warning signs that you’re heading for a crash and it’s time to stop what you're doing.

Your warning signs will be specific to you and can be anything from increased tinnitus, tingling sensations, body aches, irritability, wooziness, increased heart rate, sleep disturbance and more.

Whatever you find yours to be, stopping and resting at the first sign of them will help you to lessen the intensity of or even avoid a crash.

You’ll find that paying very close attention to its cues and reactions will be unbelievably helpful in managing your illness. Take daily notes of your activity, diet and stressors. This will help you discover your warning signs and triggers.

Picture the day ahead, and imagine your energy levels as a gas tank.

- Do you have enough gas to accomplish what you have to do?
- Or do you need to conserve gas for a particular purpose?
- If so, do whatever you can to avoid running on empty.

The hardest thing to understand on a level that will help you heal, is that the more fatigue crashes you have, the worse you will get.

The harder you push, the worse you will get.

This is an example of where those “Warning Signs” come into play. If you’re doing too much If you ignore the signs and repeatedly crash, the worse you will get and the less you will be able to do in the long run.

Our minds have amazing coping mechanisms.

If you have a minute, hour, day or week where you feel good and have few if any symptoms, you will find yourself wondering or even convincing yourself that this is it, you’re healed!

I’ve seen it and I’ve done it so, so many times. And it used to lead me into a push/crash cycle, suspending my healing as a result. The better plan is to enjoy those moments but don’t drastically increase your activity. Sit in it, *revel in it*, but continue to rest, pace and give your body the opportunity to heal.

When I finally understood this, I entered a period of feeling good, able to stay out of bed and engage in some low-key hobbies while seated on a couch or sometimes a stool, do a bit of cooking and carefully introduce occasional gentle movement. And make no mistake, I find myself doing too much more often than I'd like and have to remind myself about the value of feeling good over doing more.

Saving your energy by ignoring laundry or waiting longer to shower, by avoiding crashing, can give you the abilitly to spend time on something intellectually or emotionally fulfilling, something worthwhile that helps lift your spirits and feel fulfilled.

Taking up hobbies that align with your goals of rest can help. Depending on your fatigue and brain fog levels, things like caring for plants, puzzles, coloring books, making things with playdough or polymer clay, legos, or crochet can be calming, meditative and rewarding.

- Hobbies you can do in bed, from r/cfs

So many things steal our energy. If you're experiencing fatigue, every lifestyle adjustment you can make, every bit of stress you can relieve, will help your body to use less energy and conserve whatever energy you do have for the most important things.

LIFESTYLE ADJUSTMENTS TO DEAL WITH FATIGUE

- Showering less and when you do use a shower stool
- Getting a rolling stool for the kitchen
- Wearing comfy clothes
- Getting extra clothes and undergarments so you can go longer between loads of laundry
- Replacing old pillows with new, and consider body and wedge pillows for the most comfortable rest

- Replacing old or uncomfortable mattress if funds allow, or get a new foam mattress topper to increase comfort while resting
- Reading pillows, wedges, body pillows and extra large plush animals can increase comfort for daytime resting in bed
- Using an eye mask such as Manta
- Using earplugs such as silicone
- Use sunglasses to help with light sensitivity and the stress from long times spent in the sun or even watching tv
- Using a projector with less backlight for watching tv/movies
- Using the website “Reader” functions to help you read web pages more easily by removing distractions, changing the text presentation, or reading aloud.

  Note that you may need to add an extension to your browser or update the accessibility functions on your smartphone to enable this.
- Getting Frogg Togg or other chilling towels for heat intolerance, an electric blanket for cold intolerance
- Focusing on healthy, organic and easy to prepare foods such as pre-cooked foods and pre-cut or frozen vegetables.
- Using electrolytes for optimal hydration and drinking enough water, especially if you have or suspect POTS
  - 📝 POTS and Dehydration, Dec 2024 from the EDS.clinic
- Getting Noise canceling Bose headphones for sound intolerance or stress from long times spent listening
- Getting Compression socks can help while up and about, especially if you have or suspect POTS.
- Watching soothing, nostalgic things.
- If watching videos is too much, try listening to soothing music or stories instead.

- Filling a bedside table or rolling cart full of snacks, drinks, wipes and other self care items so you don’t have to take multiple trips a day to gather these things.
- Consider a small refrigerator near your bed for easy access to food when you’re feeling your worst.
- Getting light blocking curtains.
- A rollator can be very helpful if you have to go to the pharmacy or store. It can hold your things and provide a seat while you’re waiting.
- If you work from home, consider a bed desk. One that swings over you from the side of the bed like at a hospital will take less energy to use

TECHNOLOGICAL HELP

Technology can help you through accessibility features, AI can summarize complex papers, ring, watches and apps can monitor your body’s metrics and give you clues to the quality of your sleep, your stress levels and even predict crashes and flares.

- 📱 If you have an iPhone/Smart phone use the Accessibility features to darken your screen, set it to Gray Scale, enlarge text and use voice commands to make navigating it easier.
- 🌏 Use the Reader feature on websites to limit flashy ads,
- 🖥️ Use AI such as Chat GPT to help you read complicated studies and summarize articles.

  Be careful with AI, it is not perfect and does need double-checking, but still can be better than someone experiencing brain fog.

  The paid for versions are most up to date, which is desirable if you can afford it.

  I have used the subscription version of Chat GPT to help me organize a medication and supplement schedule inclusive of timing, synergies and interactions. I gave it specific meta-studies and websites to reference and asked it not to use mainstream sources. While I had to review, edit and ask it to update based on my findings repeatedly, my updated regimen has helped me feel better.

- ⏱️Fitbit allows you to set max heart rate alarms to help prevent you from pushing too hard.
- 📱 Heart Watch and AutoSleep apps Apple Watch can work together to keep track of your heart rate and sleep.
  - I have an Apple Watch and would not personally buy an Apple Watch for this but if you have it already, use it.
- 📱 Visible app for Long Covid can help you track symptoms.
  - You can get the armband to help you stay under your recommended heart rate.
  - It also has a pacing tool to help you learn your new limits.
- 💍 I find the Oura ring to be hugely helpful.
  - The Daily Stress encourages me to focus on wellness activities especially on high stress days.
  - The sleep tracker helped me improve my sleep (this is where it shines).
  - The tagging feature helps me learn if a new activity or med/supplement is having a positive or negative impact on my body (note you have to use it’s pre populated tags for this to work).
  - The AI is incredibly empathetic, understands chronic illness and can make suggestions on how to improve your sleep, diet, etc.

COMMON CONDITIONS

Identifying and treating comorbid conditions, you can improve your quality of life.

Similarities between Long Covid and ME/CFS are outlined in the “ME/CFS, dysautonomia and related conditions” section of 📝 Long COVID: major findings, mechanisms and recommendations January 2023 where it was found that comorbidities common to ME/CFS are also common to Long Covid.

These include Dysautonomia, Microclots, POTS, MCAS, Mitochondrial Dysfunction, Neuroinflammation, Reactivated and Latent Viruses such as Herpes Viruses, Lyme and Shingles among others, Ehlers-Danlos Syndrome, Endometriosis and more. See

These give our doctors and ourselves helpful direction when considering treatment options and testing.

- 📝 A Comprehensive Guide for COVID-19 Longhaulers and Physicians: The PASC Master Document
- 📝 Long Covid Alliance, A Comprehensive Guide for COVID-19 Longhaulers and Physicians
- 💊 Supplements & Over-The-Counter Treatments That May Help With Long Covid From Long Covid Essentials A Resources Series By The Sick Times X Long Covid Justice
- 💊 Using existing medications off-label for Long COVID from LONG COVID ESSENTIALS a resources series by The Sick Times x Long COVID Justice
- 💊 Long COVID and supplements — Bateman Horne Center
- 💊 Dietary supplements in the time of COVID-19 – National Institutes of Health (NIH)

The supplement industry is not regulated. What’s more, if you have or suspect histamine intolerance you are likely to have negative reactions from additives. I look for companies with high quality standards and research practices.

- Thorne and Seeking Health are my favorites, both are “clean” of chemicals, are involved in peer-reviewed research, and the latter is particularly interested in histamine intolerance and those with MTHFR genes.

- iHerb.com is a great resource with affordable options and good deals.
- Labdoor.com is an independent company that tests supplement for any harmful ingredients or contaminants. They grade / rank products, write reports, and publish that information for free, so consumers can confidently buy the best supplements for their health. Sadly not every type of supplement is available.

See “SEEKING MEDICAL CARE” toward the bottom of this document.

MITOCHONDRIAL DYSFUNCTION

- 📹 Mitochondrial Dysfunction and Chronic Illness, CoRE at Mount Sinai
- 📹 A Little More about Long Covid, Unraveled : Understanding Complex Illness
- 📹 Mitochondrial dysfunction in long COVID: mechanisms, consequences, and potential therapeutic approaches, April 2024
- 📝 Long COVID: major findings, mechanisms and recommendations

Things that support Mitochondrial function include,

- Supplementation such as CoQ10, NAD+, Alpha-lipoic Acid, Nicotinamide Riboside
- Deep rest through sleep and Yoga Nidra, guided meditation or binaural beats
- Diet rich in nutrients and antioxidants
- Balance your Gut Microbiome
- NIR Light Therapy
  - Be cautious if you have temperature dysregulation. Start short and slow. Benefits take time. Discontinue if you experience PEM or other exacerbated symptoms.
  - Make sure you’re well hydrated with electrolytes.
  - Do something to improve circulation such as light movement (if tolerated) and/or lying on an acupressure mat for an extended time if movement isn’t an option for you (I started with 3 minutes and quickly was able to increase to over an hour).

- Fasting
    - Studies associated are largely done on young, white males. POC and women who menstruate need to be very careful.
    - Fasting: The Practicalities by Gez Medinger

BRAIN FOG

Brain fog is particularly insidious. Some experience mild fogginess or episodes of brief confusion, while others suffer deeply with more severe symptoms.

- 📹 Akiko Iwasaki on what causes long COVID, brain fog, the Yale Paxlovid study and long COVID treatments, American Medical Association Apr 26, 2024
- 🎧 Seeking Answers in the Gut-Brain Axis, Raise the Line

Seeing a doctor, getting a referral to a Neurologist and imaging tests such as Brain MRIs with and without contrast can help rule out damage and disease.

If damage isn't found, your brain fog may be caused by NeuroInflammation. See 6.5. Future Directions of 📝 " Advancing Research and Treatment: An Overview of Clinical Trials in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Future Perspectives" , January 2024.

Things we can do to support brain function include,

- A healthy diet avoiding sugar, alcohol and processed foods
- Balancing the gut biome
- Wellness practices including meditation, acupuncture etc.
- Medications and supplements that address neurological function and lower inflammation such as LDN and LDA

- Brain teasers and puzzles such as Sudoku and Wordle can help repair neural pathways. I often do these before getting out of bed in the morning; if I'm struggling I have an indication that I should prioritize rest that day.

While there is no cure for Brain Fog, many find their symptoms improve over time. Lack of deep rest, gut dysbiosis, poor diet or lack of food exacerbate symptoms of Brain Fog.

DYSAUTONOMIA

Long Covid is a complex illness. 80% of us experience myriad confusing symptoms caused by autonomic dysfunction, commonly referred to as Dysautonomia.

- 📹 Autonomic Dysfunction, CoRE Sessions with Dr's Amy Proal and David Putrino June 2024 CoRE sessions explore the drivers and dysfunction associated with post viral conditions.
- 📝 What are the No-No's (and Yes-Yes's) of Dysautonomia? from r/dysautonomia

Dysautonomia is a dysfunction of the nerves that regulate nonvoluntary body functions, such as heart rate, blood pressure, and sweating.

- 📝 r/dysautonomia and r/POTS
- 📝 Find a Doctor, DI
- 📝 Dysautonomia International
- 📝 Dysautonomia Youth Network of America, Inc.
- 📝 National Dysautonomia Research Foundation
- 📝 The Familial Dysautonomia Foundation
- 📝 Dysautonomia Support Network

POTS or Postural Orthostatic Tachycardia

POTS is a common form of Dysautonomia experienced by many people with post viral illnesses including Long Haulers.

- 📹 Orthostatic Intolerance, Dysautonomia and POTS, Long COVID Physio

From the National Institute of Neurological Disorders and Stroke:

> “POTS is part of a group of disorders that feature orthostatic intolerance. Orthostatic intolerance is the term used to describe symptoms that occur when a person stands up and can be relieved by lying down. Symptoms of orthostatic intolerance, which often include dizziness or fainting, happen because not enough blood flows back to the heart when the person moves from a lying down or seated position to standing up.
>
> The classic symptom of POTS is a fast heartbeat. A person's heart rate may increase by more than 30 beats per minute or exceed 120 beats per minute within 10 minutes of standing. The rapid heartbeat usually improves when the person lies down again. In adolescents, the threshold for POTS is an increase of at least 40 beats per minute.
>
> POTS can also cause lightheadedness or dizziness, fainting, and palpitations which often occur upon standing. POTS may also cause exhaustion, headaches, and other symptoms. Some people may have blurred vision or tunnel vision, weakness in the legs, chest pain or other pain, fatigue, sleep problems, digestive issues, shortness of breath, and difficulty concentrating. It may be difficult for people with POTS to exercise or be physically active because of the increased heart rate, fainting spells or dizziness that occur in an upright position.

> POTS symptoms may come and go over time (called relapsing-remitting pattern). In most cases, POTS symptoms improve over time, though some symptoms may remain or last a long time."

Many doctors don't have the time to test for POTS, and the Tilt Table Test is incredibly invasive. You can request to do the NASA Lean Test. Note you need to withhold any at home treatments such as high sodium and compression to get an accurate test. It is not difficult to do at home with a BP cuff and a friend.

- 📝 NASA 10 minute Lean Test, Instructions for Providers (Bateman Horne Center)
- 📝 GENERAL INFORMATION BROCHURE ON ORTHOSTATIC INTOLERANCE AND ITS TREATMENT Peter C. Rowe, MD, Chronic Fatigue Clinic, Johns Hopkins Children's Center March 2014

What can you do?

- If you have POTS, Dysautonomia International recommends 8-10 g of sodium per day which can help manage dizziness and fatigue (See "Treatment" section of this webpage linked above). You can get this via salty foods, high sodium electrolytes (Saltt, TriOral etc), and Vitassium Salt Stick.
- Stay hydrated with 80 to 100 ounces of water per day
- Oral Rehydration Solution Recipes
- Stay cool in heat. Air conditioning, Frog Togg or other cooling towels can help. Also see, *Opinion: Life hacks from India on how to stay cool (without an air conditioner)*
- r/pots anecdote: My Doctor is a Nationally Recognized POTS expert. Sharing the stuff that worked for me.
- An example of how to make your own high sodium electrolyte drink. And here is the recipe they used.

- r/pots I’m not saying I have a cure, but these are the things I do that helped make POTS *much* more manageable
- Compression garments, particularly stockings and waist garments. Experiment to find the compression amount and type that works for you. Wear these when upright, not when lying down as the latter can cause health issues.
- Recumbent exercise to keep your heart rate low. This is not advised if you’re experiencing PEM, default to ME/CFS guidance in that case. If cautiously introducing movement, start with gentle yoga floor stretching and if symptom free and you have room in your energy envelope, try slow recumbent bikes or elliptical machines, or lap swimming. Start with very short times, keep it slow, take frequent rest stops and stop at any sign of exacerbated symptoms as that is an indicator that you have done too much for your body’s energy stores or lack thereof. Reassess whether that form of movement or approach is right for you at this time.

GUT DYSBIOSIS

Covid has been found to disrupt the gut biome. In addition to trying to balance the gut via food and pre/probiotics, it might be a good thing to do an early biome test to nip things and/or establish a baseline.

- 📹 Microbial Imbalance and Infection Associated Chronic Conditions CoRE at Mount Sinai
- 📹 Small Intestine Bacterial Overgrowth, Unraveled: Understanding Complex Illness
- 🎧 Seeking Answers in the Gut-Brain Axis, Raise the Line

I suggest BiomeSight particularly because they have an ongoing Long Covid Gut Dysbiosis study. Retest if you continue to experience symptoms. See the r/longcovidgutdysbiosis subreddit.

SLEEP DISTURBANCE

Getting quality sleep and rest is important in the healing process, but can be particularly difficult when dealing with illness that causes sleep disturbances.

- 📹 Sleep (Per Chance to Dream), Unraveled: Understanding Complex Illness
- 📹 2 Hour Long Insomnia Yoga Nidra Talk Down

Wellness activities are not going to cure you, but they can help the quality of your sleep, provide another opportunity for deep rest, lessen the intensity of some symptoms, and help you manage stress. Many wellness activities are even correlated with Immune System health.

Covid damages our nervous system and causes our bodies to remain in a state of fight of flight that can increase anxiety and cause severe insomnia. Wellness activities can help stimulate your vagus nerve and calm your nervous system down from this agitated state.

See CALMING THE NERVOUS SYSTEM for tips and resources.

Resting is not as straight forward as you think. To truly rest, to rest deeply, involves relaxing the body and quieting the mind. Consider these tips for day and night time rest,

- If meditation is new to you, start with short sessions.
- Box breathing, long, even breathes in followed by equally long, even breathes out, can help you immediately if you find yourself experiencing anxiety or an adrenaline dump.
- 4/7/8 Breathing invented by Navy Seals is another way to calm you in the immediate. Breathe in to the count of 4, hold your breath for a count of 7 and exhale for a count of 8.
- Guided meditations can be easier than trying to do it on your own by helping to keep you focused while helping you to relax your mind
- Yoga Nidra is a form of deep rest.
- Eye masks, silicone ear plugs, weighted blankets, comfortable bed and pillows, dual action melatonin, magnesium malate, Zyrtec, LDN/Low Dose Naltrexone and LDA/Low Dose Abilify all helped improve my sleep.
- Ask your doctor for help.

- Sleep apnea can be experienced by anyone of any background or body type. Get a sleep study to rule out or treat sleep apnea.
- If you can’t afford a sleep study search or ask folks at r/CPAP and r/sleepapnea for advice. This post may help whether you can’t afford it or if you have a long wait: Anything I can do to help airways without a CPAP?

POTS, PALPITATIONS + TACHYCARDIA

Heart palpitations and tachycardia are very common. It’s important to see a doctor, preferably a Cardiologist if you’re experiencing these. Thankfully, most often no disease or damage is found.

Postural Orthostatic Tachycardia or POTS is incredibly common in Long Haulers. It is an autonomic nervous system disorder characterized by an excessively fast heart rate and symptoms of lightheadedness upon standing.

- 📝 See Postural Orthostatic Tachycardia, Dysautonomia International for criteria, symptoms, classifications, treatment and more.
- 📹 What is POTS? By Dysautonomia International
- 📹 POTS Part I and 📹 POTS Part II, Unraveled: Understanding Complex Illness

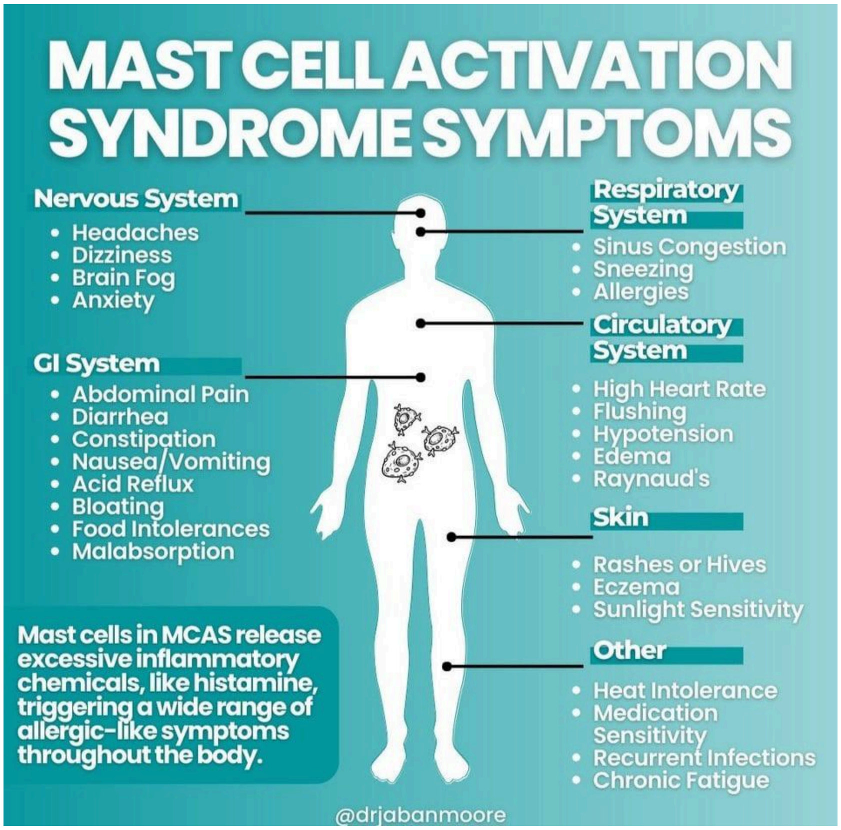
MCAS and Histamine Intolerance can also cause heart palpitations and tachycardia, among other things.

MCAS + HISTAMINE INTOLERANCE (HI)

Mast Cell Activation Syndrome or MCAS, and Histamine Intolerance or HI, are two different but often comorbid conditions common to Long Covid and other viral onsets.

- Mast cell activation symptoms are prevalent in Long-COVID
- Histamine Intolerance Introduction and Help from r/HistamineIntolerance

- [MastCellAction.org, Self Management]()



Mast cells in MCAS release excessive inflammatory chemicals, like histamine, triggering a wide range of allergic-like symptoms throughout the body.

@drjabanmoore

While eating a diet rich in nutrients and avoiding foods and drinks that cause inflammation can help, many foods that are considered “healthy” can exacerbate symptoms if Histamine Intolerance and/or MCAS has developed. These can include one or all symptoms associated, such as GI distress, tachycardia, heart palpitations, anxiety, fatigue, headaches, rashes among many others.

- [MCAS and ME/CFS]()

MCAS is a genetic condition of particularly sensitive mast cells. These can be located anywhere in the body, and are activated by 350+ substances (including our own hormones such as estrogen, neurotransmitters such as norepinephrine or autoantibodies). These can release 1300+ different substances, histamine being only one of them.

HI is a condition that does not include any mast cells abnormalities, but is a matter of the lack of DAO (Diamine Oxydase) enzyme in the digestive tract. This enzyme has an important role in degrading dietary histamine. In HI, dietary histamine and the body’s inability to degrade it is the primary problem. Those with HI should respond to DAO supplementation and a low histamine diet, while in MCAS, histamine is just one of Mast Cell mediators and associated triggers aren’t necessarily environmental but rather has an internal cause or origin.

My Personal Experience: I didn't suspect Histamine Intolerance for a long time. I misunderstood that I could have a mild form of the syndrome, and that my fatigue and tachycardia, while explained by my other diagnoses of ME/CFS, POTS and Sleep Apnea, could also have other concurrent causes.

I decided to try a Low Histamine Diet to see if it helped.

- 📝 I looked at this Food Compatibility List and created a menu of meals, drinks and snacks that I *could* eat rather than focusing on what I *couldn't*
- Within 1-2 weeks I noticed a lift in my fatigue, the kind of fatigue that felt more like being run-down than the systemic heaviness of PEM
- I slowly reintroduced foods one at a time, focusing on the most nutritionally important first and then my favorites next
- I'm lucky that my intolerance is rather mild and in the end I found that a high histamine load, rather than any one food, was my issue for the most part (looking at you Pomegranate powder! Oops)
- DAO, Quercetin and Antihistamines as well as avoiding heavy amounts of histamine foods help me manage now

If you have any of the symptoms listed I highly recommend trying a Low Histamine Diet for at least a few weeks to see if your symptoms are improved with it.

- Sighi Elimination Diet
- Through the Fibro Fog recipes
- MastCell360 recipes
- Mast Cell 360 Food List
- The TLH YES LIST
- 📹 My 5 Day LH Diet Pland + Recipes
- Histamine Chef recipes and substitutions

- So…What do you do if you're HI and broke af?
- Keeping gut healthy: A list of low histamine foods that are prebiotic
- MastCellAction.org
- r/histamineintolerance
- r/lowhistaminerecipes
- r/longcovidgutdysbiosis

If you find your symptoms are improved on the diet, here are some helpful links to get you started in your research, provided by r/mcas and r/histamineintolerance:

- 📝 Covid-19 Histamine theory: Why antihistamines should be incorporated as the basic component in Covid-19 management? NIH Feb 2023
- 📝 Antihistamines improve cardiovascular manifestations and other symptoms of long-COVID attributed to mast cell activation
- 📝 Histamine Intolerance Introduction & Help from r/histamineintolerance
- 📝 MCAS Subreddit
- 📝 Mast Cell Diseases general subreddit
- 📝 Histamine Intolerance Subreddit

Inquire at the subreddits above about how to go about seeking medical care for MCAS and/or HI.

MOLD TOXICITY

Many find that their symptoms have been exacerbated by unknown mold in the home,causing toxicity. If you know or suspect MCAS this is especially true.

In fact, even though I did not find any trace of mold in my bloodwork, I found improvement when we moved from an old, drafty house to a newer, recently remodeled house.

- 10 Warning Signs of Mold Toxicity and the connection to MCAS, EDS.clinic Sept 2024

Mold and toxins can be very taxing to a sensitive body. Address any possible mold or allergic reactions to environmental conditions and products

OTHER DAMAGE + DISEASE

There are many conditions and treatments not listed here that I don't have personal experience with. Engage with the research and communities I've listed for more options and information.

I sadly know very little about pain manifestations and symptoms. I encourage you to speak with a doctor and engage with communities dealing with Rheumatoid and Psoriatic and other Arthritis, Fibromyalgia, Ehlers Danlos Syndrome (hEDS) and other pain syndromes and diseases for information and recommendations.

GETTING HELP AT HOME

It's ok if you can't manage this alone. The answer is often help. Engage carers, private and social, friends and family, anyone who is willing to help you so that you can prioritize rest and healing. Hire services if you can afford them, apply for financial and home aides if you cannot.

RESOURCE HIGHLIGHT:

- How to Have a Great, Disabled Life: Applying for Disability, Living on Disability, Applying for Home Aides, Having Home Aides, Applying for Housing, Living in Housing, Disability Accommodations, Financial Survival, SSI Rules & Regs, Homebound/Bedbound, ME/CFS “A self-advocacy guide for anyone who is homebound or bedbound in the US. Special focus on folks with Myalgic Encephalomyelitis (sometimes called “Chronic Fatigue Syndrome”). If you are not lucky enough to have ME or CFS, you are still welcome to use this guide.“

- What Is the Date Last Insured (DLI) for Disability Benefits? In order to qualify for SSDI, you need to show that you were disabled before your date last insured.

HIRING HELP

If you can afford a service, this is the time to get it so that you can focus on rest as much as possible.

- Get things delivered
- Laundry service
- Weekly/biweekly/monthly house cleaners
- Meal delivery services
- Organizers
- Hiring an aide. Try https://www.care.com/ in the US

ASKING LOVED ONES FOR HELP

If you can’t afford services and your symptoms persist into Long Covid you will need to learn how to ask for help. If you have someone in your life that may be able to offer help, but might not know how to help or want to say and want to be supportive, ask them for help. Consider,

- If things stack up, ask them to do a little something around the house, run an errand.
- Be specific: My health is suffering, could you go to the store for me this week? Or cook me a batch meal? Or tidy up my bedroom?

MANAGING ON YOUR OWN

Sadly we can't all get full or even part time support, as much as it is needed. Regardless of our illness severity, we may be left on our own to manage things.

- 🎧 Providing Physical Therapy Services at Home, Raise the Line

MILD ILLNESS

Prioritizing rest isn't easy, but it's imperative that you do whatever is necessary to avoid crashing so that your disability doesn't progress.

- Schedule rest time during the day every day.
- Schedule appointments one or multiple days apart, meetings one or more hours or days apart.
- Schedule entire days of every other day, every third day, whatever you can manage.

MODERATE ILLNESS

For those of you that can manage some self care, there will inevitably be things that you must take care of yourself. If you're struggling but pushing to get things done and otherwise too exhausted to do the things that are important to you, consider changing your standards. At least once a week, let go of tasks in favor of something you really enjoy.

- Leave laundry unfolded and in a designated "clean" basket. Get hooks instead of hangers and drawers. By letting things go, and establishing different standards will give you more bandwidth to spend time on something more important.
- Ask a loved one to help you set up automatic payments for your bills and let unimportant mail pile up. Maybe that will save you energy so that you can feed yourself.
- Ask a loved one to bring you a meal so that you have the bandwidth to have a conversation with them or play with your kids.
- Ask or hire someone to tidy the kitchen, bathroom or house. Maybe that will allow a bit of energy for you to sit outside in the sun for an hour.
- Get a cart, mini fridge, microwave bedside so that you don't waste energy walking to/from the kitchen repeatedly. Maybe then you can manage putting something simple together for dinner.

- Get a rollator or rolling stool to navigate the house. Maybe you will have energy to watch your favorite movie.

SEVERE ILLNESS

If you're really struggling,

- Watch Youtube videos of people walking through landscapes, ASMR baking and gardening videos.
- How to Be Homebound and Bedridden from How to Get On
- Long Covid and Chronic illness subreddits will have a lot of information; search these or post to ask for help specifically for your location. Explain you're too fatigued and or brain fogged to research and you're worried you're falling through the cracks.
- Engage the subreddit communities for help, advice or even commiseration.
    - r/covidlonghaulers, r/cfs, r/dysautonomia, r/POTS, r/longcovidgutdysbiosis, r/histamineintolerance, r/mcas, r/heds
- Ask for help by social services at your local and national level.
- Information about Disability Benefits from an American Disability lawyer
- Former SSA disability attorney AMA

EMOTIONAL IMPACTS

If you're dealing with Long Covid, you will experience the emotional impact of chronic illness, including the loss of your former life, identity and relationships.

I found my Long Covid to be a complete identity shift, and had to mourn the loss of my former self. Therapy with a chronic illness and covid conscious therapist can be so helpful if you find yourself disabled by this. Long Covid Doctor Map.

- Find a Covid-Conscious therapist
- Find an International Covid-Conscious therapist

The following discussion and review help us understand the impacts of managing our complex illnesses on our mental health, the biological dysfunction that can lead to depression and anxiety, and how doctors and the medical system have failed sufferers of post-viral illnesses by minimizing and psychologizing rather than acknowledging the clear physical neurological dysfunctions our bodies have.

- 📹 The Psychological Impacts of Complex Chronic Illness, CoRE at Mount Sinai
- Me/Cfs: What Psychiatrists Need To Know from Doctors with ME
- A review on cognitive behavorial therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS
- Gut microbes have an unexpected link to anxiety

Toni Bernhard's interviews and her book *How To Be Sick* helped me understand my new life and identity shift caused by my disability.

- How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers by Toni Bernhard
- Interview with Toni Bernhard on the Art and Science of Living with Chronic Illness, on the Unconditional Healing podcast

RELATIONSHIPS

Chronic illness can and does affect our relationships. Be mindful of caretaker fatigue and loved ones frozen with fear. Also be prepared to establish good boundaries for yourself. It's a delicate balance to take care of your loved ones when you don't have the energy no to care for yourself.

- Communicate what you can and encourage loved ones to research your illness so that they understand. Often we look healthy, which is why it's called an invisible illness.
    - 📹 THE UNRAVELLING - A SCIENTIST . AN ARTIST . A FATHER
    - How To Talk To Your Loved Ones About Covid

    - I Love You. Please Find Someone Else. “In sickness and in health” may sound romantic — until you’re sidelined with a chronic illness. NYTimes Opinion
    - 📹 UNREST Feature Documentary (With Captions and Multilingual Subtitles)

- If you can, avoid putting too much on any one person.
- Try to engage your loved one in topics other than illness.
- Try to thank them often for their support.
- Be mindful that your illness reminds others of their own vulnerability. It’s not an excuse for poor behavior, but rather a possible explanation.
- Loved ones may not know what to say or how to help, have strong reactions and even aversion to you as a chronically ill person. This is sad and all too common.

TOXICITY

If you find yourself in a toxic environment in which you feel unsupported, demeaned or attacked and are not able to move or live on your own, seek support on r/covidlonghaulers.

- The Price and Payoff of a Gray Rock Strategy, Psychology Today
- Applying for disability resources can help in becoming more independent.
    - How to Have a Great, Disabled Life
    - Information about Disability benefits from an American disability lawyer. : r/cfs
    - Financial Aid for Long Covid sufferers in the US? r/covidlonghaulers

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YOUNG PEOPLE WITH LONG COVID

Sadly our youngest people are experiencing debilitating post covid symptoms and it is difficult to find research and treatments appropriate for their developing bodies.

- Characterizing Long COVID Symptoms During Early Childhood, May 27, 2025

Here are some resources to get you started.

- 🎧 Guidance for Treating Children with Post-Acute Infection Syndromes, Raise the Line
- RECOVER Kids
- Long Covid Kids Toolkit
- American Academy of Pediatrics: Resources on Long COVID in Children
- Children’s National Pediatric Post-COVID Program
- Long Covid Studies on Children from r/ZeroCovidCommunity

Believing and finding ways to support your child are the most important things.

- 📹 THE UNRAVELLING - A SCIENTIST . AN ARTIST . A FATHER
- Too many children with long COVID are suffering in silence. Their greatest challenge? The myth that the virus is ‘harmless’ for kids
- Long-Haul COVID-19 in Children and Teens
- Long Covid Families: Pediatric Pacing Guide and a Tip Sheet Talk About Long Covid with Your Child’s Doctor
- Long COVID in Kids: A Path to Recovery
- Supporting a child with long COVID – tips from parents of children living with the condition
- Unicef, What parents need to know about long COVID in children Pediatric infectious diseases specialist Dr. Carlos Oliveira explains long COVID symptoms and treatments.

Calming The Nervous System for Young People:

- A low weight weighted blanket for sleep
- A large squishmallow friend to sleep and rest
- Brown or white noise machine
- 432 hz sound while sleeping
- Engage in wellness activities to support the vagus nerve by making them a game
    - Gentle Yoga for kids
    - Humming

  - 📹 Calming Exercises for Kids: Breathing and Stretching
  - Seated Yoga for Toddlers
  - 📹 Teaching them about Box Breathing. Practice with them and explain how to use it when emotional or experiencing sleep disruption

SEEKING MEDICAL CARE

There is no cure and no approved treatment protocol. Beware of any doctor or company that claims they have “the” answer to Long Covid, or an over-simplified explanation for your illness, especially if they are charging a lot of money or trying to sell you something.

Long covid is a complex and chronic disease, and every body experiences it differently.

- 🎧 What Clinicians Can Learn About Managing Uncertainty, Raise the Line
- Always ask doctors for peer-reviewed evidence for the intervention(s) they’re proposing as a way to ensure you are getting good advice. Any knowledgeable, studied medical professional, the kind that you want caring for you, will be willing and able to share.
- When a doctor proposes a treatment or intervention, ask what they are trying to encourage, what are they trying to discourage; what are the risks associated and what are the potential benefits?

I also find it helpful to remember that my relationship with my doctor is a collaborative effort, not a paternalistic relationship. To that end,

- I get to decide what treatments and risks I take.
- It’s not acceptable for a Dr to push a treatment.
- Suggest yes. Explain yes. Pivot yes. Push no.

In early days, you want your doctors to order bloodwork and tests to rule out common, well understood deficiencies, damage and disease.

- Patient Advocate here: I commonly see these go untested or interpreted incorrectly


From covidlonghaulers community on Reddit

When talking with health care workers, focus on your symptoms, how they feel in your body, and how those symptoms affect your quality of life.

- How To Get Doctors To Listen When You're Being 'Hysterical', Refinery 29 by SARAH GRAHAM LAST UPDATED 8 JANUARY 2023 on r/cfs

It's worth it to address everything you can, even if it only leads to improving your symptoms by 1%. If you stack up a bunch of 1,2 and 3 % improvements it add up to a noticeable improvement over time.

Describing your life before symptom onset vs your life now can be helpful. Examples:

- I used to be able to climb stairs without even thinking about it. Now one flight takes 10 min because I find myself having to rest before, during and after.
- I used to be able to run/walk/hike daily, but now walking to the bathroom or kitchen leaves me winded and exhausted.
- My fatigue/breathlessness/heart rate/dizziness are severely impacting both my and my partner's quality of life
- I'm motivated and I want nothing more than to work, exercise and socialize. My symptoms are preventing me from doing any of this.

Keep a diary of symptoms including dates of onset and acute viral infections to help you see trends and how symptom weight changes over time (hopefully for the better). These can help you and your doctor understand your symptoms, triggers and disease progression.

- Visible app for Long Covid can be helpful, as can a spreadsheet with color coding.

Not enough doctors understand Long Covid, ME/CFS, Dysautonomia, POTS, MCAS, Histamine Intolerance, HEDS etc.

This list that may help you find someone, Long Covid Doctor Map. If you're having difficulty, reach out by posting on one of the illness subreddits for any recommendations in your area.

Heartbreakingly sad is knowing that it takes 10-20 years for research to be adopted in a clinical setting. What's more, there is a long history of medical abuse, racism, misogyny, ableism and even eugenics that persists today.

I find it helpful to remember that doctors are people taught by and working in a broken system. Doctors are good at memorizing things, and they may or may not have gotten the best or worst grades in their graduating class. They are taught to prescribe but are not taught how to deal with chronic illness.

They have many biases, often dismiss things as "too rare" to be considered. Too often they've become jaded and consider patients to be overly emotional, hypochondriacs, dumb, unhealthy, anxiety ridden and/or just looking for attention. There are many accounts of this on the illness subreddits I've listed.

> "I think my mood is actually pretty good for someone who feels as chronically lousy as I do" u/RareStick9077 is something you can say to avoid being placed in the "It's just anxiety, try yoga and take this mood stabilizer" category that receives poor or no treatment.

If you find yourself severely disabled and in danger of mistreatment of your condition by the medical community, consider the following letter. If you are not in danger, keep this letter saved in case you find yourself in an unexpected position.

- Letter for Severe Patients to Show their Psychiatrists if They're in Danger of Being Hospitalized
- Link to the letter itself
- Cognitive behavioural therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective.Re-analysis of a Cochrane review
- Treatment Harms to Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
- We are Failing People with Very Severe ME/CFS
- ME/CFS: What Psychiatrists need to know

It can help to bring a friend or loved one to appointments, particularly a male (sad but true, even with female doctors), that repeats what you say and pushes for help to specifically address your concerns if you are being ignored. They can bear witness and take notes on your behalf.

Some doctors are open to hearing about your thoughts/research and others (sadly more often) will label you as a hypochondriac if you share your thoughts on Long Covid. Be careful to understand which type of doctor you are dealing with.

Many have found luck working with traditional western as well as alternative and integrative medicine.

When making appointments, consider the practicalities:

- It takes a lot to drive to any appointment, even as a psssenger, and to walk to and from the car.
- Ask for virtual or phone appointments when you can to conserve your energy.
- Spread out your appointments to give you a chance to recover between them.

If you need to stay or have an out-patient procedure at a medical facility or hospital, reach out to their Patient Relations advocate.

- Guide to Requesting Accomodations for COVID-Safe Medical Care, CITIZENS COVID COALITION

You may have been experiencing perimenopause, ADHD or any number of other conditions before your covid infection that has overlapping symptoms with Long Covid. Your covid infection may exacerbate your previous symptoms and you may get entirely new ones.

It can be helpful to prepare an illness and symptoms timeline, including any diagnoses before your Covid infection(s). Doing so should put in full relief for both you and your that while these conditions certainly don't help matters, they may not be the driving force behind your illness.

It’s important to get bloodwork and imaging to both rule out anything obvious and treat anything that might be found.

I consider it a red flag when a doctor immediately pushes SSRIs, SNRIs or exercise, graded or otherwise. It’s an indication that they do not understand the complex chronic illness they’re dealing with and might have made assumptions that your symptoms are psychosomatic or due to laziness.

- The Updated NICE Guidance Exposed the Serious Flaws in CBT and Graded Exercise Therapy Trials for ME/CFS, NIH May 2022
- Find a COVID-conscious therapist

I am not saying never take medication for anxiety or depression. That very well may be helpful for you. I’m just asking that you be mindful when making that decision and ask for the research and considerations your Doctor is using to make their recommendations.

Likewise, therapy can be very helpful particularly in grappling with your new chronic illness and the loss of your former life and self.

- Me/Cfs: What Psychiatrists Need To Know from Doctors with ME

I'm also not saying never move again either. Gentle movement within your body's limits and energy envelope, when you aren't experiencing fatigue, can be beneficial even for those suffering from ME/CFS.

The following can help you and your general practitioner guide your care.

- A Comprehensive Guide for COVID-19 Longhaulers and Physicians: The PASC Master Document
- Long Covid Doctor Map
- Long Covid Alliance, A Comprehensive Guide for COVID-19 Longhaulers and Physicians
- Dysautonomia International, For Patients
- Dysautonomia International, POTS
- NASA Lean Test for Orthostatic Intolerance, Bateman Horne Center
- Long Covid Science, Research And Policy Ziyad Al-Aly Aug 2025
- Long Covid: Major Findings, Mechanisms And Recommendations April 2023
- Long Covid Essentials: New Resources From The Sick Times December 19, 2024
- How To Talk To Healthcare Providers About Long Covid
- The Updated NICE Guidance Exposed the Serious Flaws in CBT and Graded Exercise Therapy Trials for ME/CFS, NIH May 2022
- Me/Cfs: What Psychiatrists Need To Know
- Diagnosis And Management Of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - Mayo Clinic Proceedings Oct 2023

- Key Pathophysiological Role Of Skeletal Muscle Disturbance In Post Covid And Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (Me/Cfs): Accumulated Evidence First Published: 27 December 2024
- Exertional Exhaustion (Post-Exertional Malaise, Pem) Evaluated By The Effects Of Exercise On Cerebrospinal Fluid Metabolomics–Lipidomics And Serine Pathway In Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Published Feb 2025
- Muscle Abnormalities Worsen After Post-Exertional Malaise In Long Covid Published Jan 2024

DIAGNOSIS and DISABILITY SUPPORT

Diagnosis can be difficult, particularly because there’s no test for Long Covid and few tests for associated conditions. Long Covid is a diagnosis of exclusion, while others like ME/CFS and POTS have diagnostic criteria to meet.

You’re likely to go through a long process of blood testing snd imaging to rule out other causes. It can be both relieving and frustrating to be continually told that results are normal. You don’t necessarily want to have any of the things you’re being tested for, but you do want answers and better yet a clear treatment plan.

Going through this process can be helpful when you are applying for state or national assistance programs that require proof of disability in order to be approved.

- A Guide to Social Security Income for ME/CFS
- Information about Disability Benefits from an American Disability lawyer

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LONG COVID CLINICS + STUDIES

Sadly there are fewer and fewer clinics but there are still some, particularly at research hospitals and universities.

- Long Covid / PASC Clinics USA, Public Health Action Network

If you are near enough to a clinic to be able to get there at least once, ask your doctor for a referral or apply on their website if available.

Most of these clinics require you to see them in person, at least initially. There's sadly few if any studies available for those that are most severe and unable to travel. The Mayo Clinic in Ohio has an intensive program that requires you to see multiple doctors and undergo many tests within the span of 1-2 weeks depending on what they find. It is expensive, but depending on your situation may be worth it. .

Whether Mayo or any other clinic, set your expectations before going. The practitioners at these clinics may or may not know how to help, may or may not have good advice. Search the r/covidlonghaulers subreddit for information on the particular clinic or doctor you may be seeing. Post an inquiry if you don't find anything.

- Ezra's Long Covid Studies List

Some studies are quite invasive and should be considered carefully. Others may be a waste of your energy with no chance of benefit to you or possible harm.

I've personally had some success with studies through Stanford and UCSF.

Please avoid trials exploring exercise intolerance, wellness practices, and those that are pushing psychological pathologies. Long COVID and its associated symptoms and disease involves serious physiological and neurological dysfunction that is well documented.

- The Updated NICE Guidance Exposed the Serious Flaws in CBT and Graded Exercise Therapy Trials for ME/CFS, NIH May 2022.

We do not need more studies exploring yoga, psychosis or the incredible dangers of exercise.

Note: Ageless Rx and Healthspan are options for an LDN and other commonly used off-label medications that have been embraced by the anti-aging community. These are great resources if you can't find a doctor to prescribe.

- How I got LDN in the UK
- LDN Research Trust, International Find a Prescriber

TAKING PRECAUTIONS and AVOIDING VIRAL INFECTIONS

Prevention is the best medicine, and given any Covid infection damages your immune system; at best for a short time and worst permanently, it is vital that you avoid Covid reinfections, and any other viral infections, as each one can worsen your symptoms and invite new damage and disease.

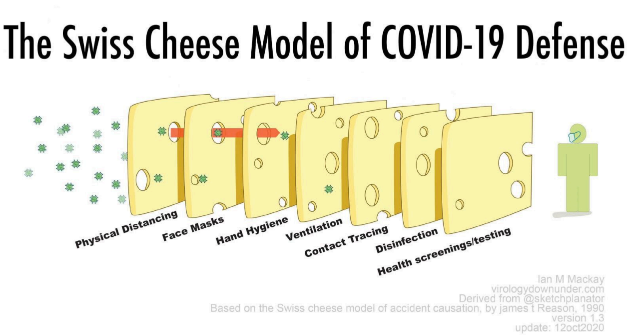
Covid damages our immune systems. Avoid reinfection of Covid or any other virus because you can get worse, you can develop more health issues and you can compromise any progress that you've made with any new infection. By avoiding more infections you will give your body time to heal and won't risk losing whatever health you have and any progress you've made.

- Studies consistently show (through each variant) that 10% of people develop Long Covid after infection.
- From there 50% of those develop ME/ CFS.
- If you're getting infected multiple times, those odds go up.
- What's more, you can experience a setback if you've made any progress in healing.

Given this, it's important, vital even, that you avoid viral infections, including Covid reinfection.

- You Have To Live Your Life, A resource for COVID-19 research and information

Please take any and all precautions available to you. A layered or "Swiss Cheese" approach that includes masks as the most effective tool available to us is highly recommended.



Layers other than masks include vaccines (as appropriate for the individual's health status), HEPA air filtration, NAAT and RAAT testing, and CPC mouthwash, neti pot nasal rinses, nasal sprays, hand washing to prevent other diseases such as Norovirus and Flu commonly spread by fomites etc. Tips:

- Global mask bloc directory
- See r/masks4all, r/AirFiltration, r/ZeroCovidCommunity, r/PlusLife and r/AirPurifiers for resources and support
- Avoid anyone with symptoms of illness and remember that up to 50% of Covid infections are asymptomatic or presymptomatic.
- See CIDRAP, Center for Infectious Disease Research and Policy for up to date information on viruses in the US.

- People's CDC guide to Covid testing
  - At home NAAT such as Metrix and PlusLife among others are available now. These are highly sensitive pcr-like tests with up to 97% accuracy. They are expensive upfront, but PlusLife in particular can be less expensive than RAATs overtime, and can also test for flus and rsv (note that the combo tests are a bit less accurate).
  - See r/PlusLife and/or Virus.Sucks website to inquire about a discount.
  - RAAT tests are helpful but not sensitive and therefore are only 60% effective. Multiple tests 48 hours apart are required to catch a positive. They are particularly bad at catching asymptomatic infections.
  - Personally, before I consider unmasking with anyone I require both no symptoms of any kind and a negative PlusLife test taken at my home while masked.
- The Four Rapid COVID PCR Tests You Can Take at Home (and Why You Should), PCR tests are far superior to rapid antigen tests—and now you can get them for home use.
- How to build your own Corsi-Rosenthal Box
- Clean Air Kits
- Yale Medicine overview of available Covid vaccines

HOPES

I'm so thankful for the r/covidlonghaulers, r/zerocovidcommunity, r/longcovidgutdysbiosis, r/CFS, r/MCAS, and r/HistamineIntolerance communities, especially those that have been going for decades. The research, personal experiences and support posted daily help each of us deal with this complex illness we find ourselves dealing with.

My hope is that you find some direction and relief of symptoms after reading this and the articles, studies, subreddits and foundations linked.

If you find yourself in remission or recovery of your acute or long Covid symptoms, I hope that you share what worked for you so that others can benefit from your experience.

I also hope that you become an empathetic ally to those of us that continue to deal with the cruelties of this disease, the ongoing pandemic and failure of public health around the world.

RESOURCES

📝= Reading 🎧= Podcasts 📹= Videos 💊= Supplements + Medications

- 📝 Covid Safety Handbook
- 📝 Zero Covid Resource Roundup Reddit Post

LONG COVID MEDICATIONS and SUPPLEMENTS

- 💊Paxlovid discount
- 💊Using existing medications off-label for Long COVID from LONG COVID ESSENTIALS a resources series by The Sick Times x Long COVID Justice
- 💊Supplements & Over-The-Counter Treatments That May Help With Long Covid From Long Covid Essentials A Resources Series By The Sick Times X Long Covid Justice
- 💊Ageless RX for Metformin, Low-dose Naltrexone in the US
- 💊Healthspan
- How I got LDN in the UK
- LDN Research Trust, International Find a Prescriber

MEDIA

- 🎧 📹 Unraveled: Understanding Complex Illness on Youtube
- 📝 The Sick Times
- 🎧 Covid Long Haulers podcast
- 🎧 Post Viral, A Recovery Podcast
- 🎧 Make Visible, Understanding Complex Illness
- 🎧 The Osterholm Update podcast from CIDRAP
- 🎧 Public Health is Dead podcast
- 🎧 Death Panel podcast

RESEARCH / ARTICLES

- 📝 Health Rising
- 📝 CIDRAP, Center for Infectious Disease Research and Policy
- 📝 Yale Medicine, Long Covid Blog, Articles and Research
- 📝 Science for ME
- 📹Akiko Iwasaki on what causes long COVID, brain fog, the Yale Paxlovid study and long COVID treatments, American Medical Association Apr 26, 2024
- 📝 Acute and postacute sequelae associated with SARS-CoV-2 reinfection, NIH Nov 2022
- 📝 Post acute Sequelae of SARS-CoV-2 Infection in the Pre-Delta, Delta, and Omicron Eras, New England Journal of Medicine, July 2024
- 🎧 Long COVID: The Experts Were Wrong with Dr. Ziyad Al-Aly and Hazie Thompson, Public Health Is Dead podcast Episode 1, Nov 2024.
- 📹why is EVERYONE more SICK?
- 📝 Everything "That Friend" Wants You to Know About Covid, We're scratching the surface July 2024
- 📝 Long COVID puzzle pieces are falling into place – the picture is unsettling July 18, 202
- 📝 Responses to “Back to Normal” and “You Have to Live Your Life” sentiments

REDDIT / POSTS

- 📝Sub-reddits: r/covidlonghaulers, r/dysautonomia, r/POTS, r/longcovidgutdysbiosis, r/histamineintolerance, r/mcas, r/cfs, r/zerocovidcommunity, r/airpurifiers
- 📝 A Zero Covider’s excellent collection of studies on Covid and Long Covid
- 📝 Psa: How To Get Your Primary Care Doctor To Take You Seriously.
- 📝 Twenty-Eight Days on Oxaloacetate--Update
- 📝 Individuals with MTHFR Genetic Mutation Exasperated by COVID-19

COMMUNICATION

- 🔗 How To Talk To Your Loved Ones About Covid
- 📹 UNREST Feature Documentary (With Captions and Multilingual Subtitles)