With the exception of chronic fatigue syndrome (ME/CFS, M.E.), post-infectious illness states – which occur when someone remains ill after a pathogen has apparently been vanquished – have received very little attention in medical research. The studies that have been done outside of ME/CFS have mostly served to document that these problems exist. Since the clinical studies in ME/CFS are rare, tend to be small, and usually focus on long-duration patients, they may not provide a lot of help either.

COVID-19 long haulers might be heartened to know, though, that the NIH started a small but incredibly in-depth study of **early post-infectious onset ME/CFS** patients; i.e. people who were in your situation a couple of years ago after infection with a different pathogen. That study is now informing a similar study underway on the COVID-19 long haulers.

Avindra Nath is applying the insights he's learned from ME/CFS patients to a long-hauler study.

Open Medicine Foundation (OMF)-funded ME/CFS researchers are also doing complete molecular analyses of long haulers. Both of these studies bring an in-depth knowledge of the post-infectious state to the table.

Unfortunately, the National Institutes of Health (NIH) has not yet embraced the long-hauler issue and more studies are needed to provide insights into what's happening with you and so many people with ME/CFS.

Other encouraging news includes the post COVID-19 treatment centers that have opened up and the many tracking projects that will provide valuable data we can use to push for more funding.

In short, if you have to come down with a post-infectious illness, this is easily the best time to come down with one.

Suggestions On How To Get Through This

But what to do in the meantime? Is there a way to increase your chances of recovery? Are there things you should be doing now? If COVID-19 is similar to the infectious events that triggered conditions like chronic fatigue syndrome (ME/CFS) in the past, there are no guaranteed ways to return you to health. Decades of reports from ME/CFS patients and doctors may be able to provide some help on what to do and what not to do.

Here are some basic and simple things that might help.

Taking COVID-19 Seriously

The First Thing is to Take Post COVID-19 Problems Seriously

Thinking your symptoms are something you can push aside or work through can be a recipe for disaster. Most people with COVID-10 recovery problems will not, thankfully, get ME/CFS but some likely will, and ME/CFS is not something you want in your life.

Studies indicate that chronic fatigue syndrome (ME/CFS) is more functionally disabling than heart disease, multiple sclerosis, kidney failure and other serious diseases. People with ME/CFS have a **lower quality of life** than people with cancer, stroke, renal failure and schizophrenia. Twenty-five percent are **home or bedbound**. One study found that only an astonishingly low 13% were employed full-time.

Please take your post-COVID issues seriously.

Pacing

Provide energy for healing

Pacing, you've probably realized by now, is critical. Studies have shown that people with ME/CFS who stay within **their energy envelope** and **avoid the push/crash cycle** tend to have fewer symptoms and qualitatively better lives. Pacing is believed to open up energy your body needs to devote to healing.

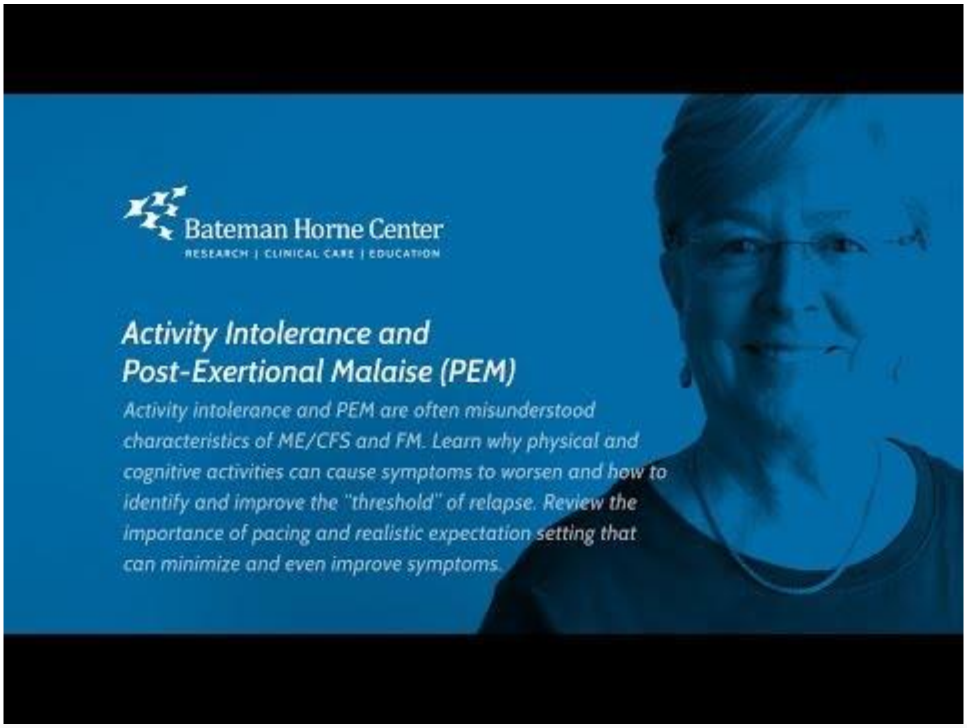
The hardest, and perhaps the most important, advice for anyone facing post-infectious problems is simply to pace, pace, pace. Rest. Don't overdo. Pace mentally as well as physically. Try and calm your body and mind down and give your body a chance to heal.

Many people with ME/CFS, in retrospect, rue their attempts to push through these illnesses, which led to worsened health. Health Rising's survey asking people with ME/CFS **what they would have differently** if they had only known indicated that many people felt that they pushed too hard and tried to return to normal life too quickly.

Different techniques from **Counting Your Spoons,** to **living inside your energy envelope**, to using **heart rate variability** (HRV) readings to manage your activity levels for better health, can be found in **Health Rising's Pacing and Exercise resource sections.** Dr. Lapp provides **a nice guide here**.

Bruce Campbell's **CFIDS Self Help** site provides the most in-depth information on pacing. (Campbell used pacing to recover.) It provides courses, checklists and a wealth of information on how to manage these diseases and "**How to Make a NOT To DO List**". We're very lucky to have it. Also check out Bruce Campbell's book, "**Managing Chronic Fatigue Syndrome and Fibromyalgia: Feel Better, Take Charge, Regain Hope**".

Check out Dr. Lucinda Bateman on Activity Intolerance and Pacing



Activity Intolerance and Post-Exertional Malaise (PEM)

Activity intolerance and PEM are often misunderstood characteristics of ME/CFS and FM. Learn why physical and cognitive activities can cause symptoms to worsen and how to identify and improve the "threshold" of relapse. Review the importance of pacing and realistic expectation setting that can minimize and even improve symptoms.

Crash and Flare Busters (?)

Help your body to heal and limit the effects of crashes

Check out some possible crash and flare busters for those inevitable times when you go too far. Note that these are suggestions and have not been validated.

- **Crash / Flare Busters For Chronic Fatigue Syndrome and Fibromyalgia**

Coping

Rebalance the autonomic nervous system, tamp down the fight/flight system, reduce the stress chemicals that promote inflammation

Coping can make a difference – not just emotionally and mentally – but also physiologically. Studies have shown that both stress responses are disturbed in ME/CFS, and some believe the disease is at its heart a stress response disease. Take it from Pema Chodron – a world renowned Buddhist with ME/CFS – who describes how mindfulness and pacing has helped her. (From **the Bateman Horne Center**).

Check out how Donna Jackson Nakazawa, a journalist with a serious autoimmune disease, improved her quality of life and health using mindfulness and meditative practices and yoga.

The Last Best Cure Blog Series For Fibromyalgia and Chronic Fatigue Syndrome (ME/CFS)

How to Be Sick – from the widely acclaimed book series by Toni Bernhardt, Buddhist practitioner with ME/CFS, on how to have as high a quality life as possible while being sick. She just came out with a **compact version**. Other books in the series include “**How to Live Well with Chronic Pain and Illness: A Mindful Guide**” and “**How to Wake Up: A Buddhist-Inspired Guide to Navigating Joy and Sorrow**”

Mindfulness Based Stress Reduction (MBSR) – John Kabat-Zinn developed the meditative and mindfulness practices in the MBSR to help people with chronic pain. Courses are offered in many hospitals and clinics. Kabat-Zinn’s seminal book “**Full Catastrophe Living**” has been lauded by many. (Check out the **Audio version** – you’ll love Kabat-Zinn’s calming voice.)

Breathe Deeply

Restore autonomic nervous system balance, turn down the stress response and reduce inflammation

One of the first things Staci Stevens, an exercise physiologist with ME/CFS, does with her clients is teach them how to breathe more deeply. Breathing deeply enhances the activity of the rest/digest system and calms down the fight/flight system – which is overactivated in ME/CFS.

Breathing Techniques for Chronic Fatigue Syndrome and Fibromyalgia

Seeing Doctors

Get relief and support

“I wouldn’t have wasted a second seeing doctor after doctor who were not specialists in ME/CFS, especially at the beginning when I was so desperately ill and every trip took so much out of me. I would have realized that the extra stress of having people refuse to help me or judge me or blame me just made things vastly worse. I would have found a sympathetic and supportive doctor right away.” **Curiosity**

You may not be able to find a doctor who knows much about post-infectious illnesses or ME/CFS, but hopefully you can find a doctor who treats these illnesses with respect.

Ditch Bad Doctors – if you hit a bad doctor, don’t get blue in the face and waste your energy on them – they’re not worth the trouble. Instead, move on as quickly as possible. Your job is, after all, to find a good doctor.

Educate Your Doctor – we don’t know how closely those who fail to recover from COVID-19 will resemble people with ME/CFS, but as we don’t have guides for post-COVID-19 patients, perhaps those put together for ME/CFS will help.

- **Do You Have ME/CFS?**

It might help to know if you meet or about to meet the criteria for ME/CFS. The criteria requires that you have symptoms for six months, but if you’re not there yet, you can at least get a grasp of what ME/CFS is. If you do meet the criteria, you should know that you’re part of an active community that is advocating hard for you.

- **Take the quiz** from the Solve ME/CFS Initiative (SMCI).

#MEAction will host a panel discussion with ME/CFS experts on August 29th at 3:00 PM PST to teach clinicians how to recognize and manage ME. Clinicians and med students **register now.**

Health Rising's End of the Year Donation Drive

If finding out about cutting-edge research and treatments in ME/CFS, fibromyalgia, long COVID, and related diseases is helpful for you, please support Health Rising in its 2021 year-end fundraising drive.

Paypal, checks, Amazon gift cards, or even bitcoin work for us.

Use the donation widget on the right-hand side of the page **or find out more here.** Thanks!

Maximize your doctor appointments

Doctor appointments can be particularly tough. You have a lot of symptoms, your mind is whirring, your short-term memory is pretty much shot and your health is at stake! In short, you need to get organized like you may never have before. Check out a bunch of resources on how **to get organized**, talk to your doctor about ME/CFS or chronic pain, track your symptoms, etc.

Check out the Solve ME/CFS Initiative's webinar: "Empowerment in the Doctor's Office: Overcoming White Coat Syndrome" to find out how to have more effective doctor's office visits

ME/CFS Information Packets for Physicians May Help

- **Check out Workwell's MedBridge course on identifying and managing ME/CFS. –** Workwell Foundation offers a **2-part continuing education course** for physical and occupational therapists through Medbridge that addresses many of the complex issues facing the rehabilitation of long-term COVID-19 patients. Workwell has dedicated over 20 years of research to understand the metabolic, pulmonary, and cardiac complications of people suffering from post-viral ME/CFS. (**from Caroline Christian**).
- "**Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: What Every Family Physician Needs to Know**" – published in the Family Doctor: A Journal of the New York State Academy of Family Physicians. Produced by ME/CFS expert Dr. Susan Levine, Mary Dimmock and Terri L. Wilder, the article provides a basic introduction to ME/CFS. A good start – not too long, not too short – for doctors who are willing to learn.
- **The IACFS/ME Primer for Clinicians** – extensive primer on diagnostics and treatment put together by ME/CFS experts. Provide it for more interested doctors who are willing to invest some time.
- **Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer** – Extensive primer for doctors treating young people. **Share the IOM report** (2015) and its diagnostic algorithm with your doctor. The Institute of Medicine (IOM) is the most highly regarded medical reporting group in the United States.
- **Unrest** (2017) – Tell your doctor she/he can get continuing medical education (CME) credits for viewing the Sundance Award Winning Documentary. It's a powerful and evocative film centered on severely ill ME/CFS patients.

Check Out What ME/CFS Experts Are Doing

Diagnosis and Management

While you probably don't know if you have or will have ME/CFS, you might want to check out how a knowledgeable doctor assesses the disease. This doctor, Dr. David Kaufman, was formerly an HIV specialist and he now works with another infectious disease specialist in the San Francisco Bay area.

Dr. Bela Chheda, An Infectious Disease Doctor Talks on ME/CFS

Now specializing in ME/CFS, Dr. Bela talks about her treatment approach to ME/CFS.

From Infectious Disease Specialist to ME/CFS Expert: Dr. Bela Chedda Talks

The Bateman Horne Center Video Series

The Bateman Horne Center has produced a series of video presentations by longtime ME/CFS practitioner Dr. Lucinda Bateman. This one provides basic facts on diagnosis and treatment.

Getting the Right Diagnosis

ME/CFS and FM present as complicated illnesses and getting the right diagnosis can be challenging or seem like an impossibility. Learn how to distinguish between these two diseases and recognize co-morbid conditions.

Check out more resources including Health Rising's **How To Diagnose ME/CFS,** including the many comorbid diagnoses associated with it and disease mimics.

Wondering if your symptoms match those found in chronic fatigue syndrome (ME/CFS) and/or fibromyalgia? Check out "**In Their Own Words: Chronic Fatigue Syndrome and Fibromyalgia Patients Describe Their Symptoms**"

Getting Restorative Sleep

Poor sleep is a hallmark symptom of ME/CFS and FM. Not getting a good night's sleep can worsen symptoms. Dive into the mechanics of good sleep with Dr. Bateman and learn why sleep disturbances occur and how to implement strategies that improve them.

Restorative Sleep

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Check out more sleep resources in **Health Rising's Sleep Resources** section including: **Head's Up – An easy way to improve sleep? A bed of nails for better sleep? How to improve your sleep hygiene –** good sleep practices; **biofeedback saves one person; Health Rising's Sleep Series**; its **1000 person Sleep Survey** and more.

Chronic Widespread Pain

Pain is one of the most troubling and hard-to-manage symptoms of ME/CFS and FM. Dr. Bateman teaches about the various types of pain, how pain is amplified, and treatment strategies to improve your own pain management.


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Getting the Right Diagnosis

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Instead of opioids and over-the-counter analgesics, some people find low dose naltrexone (LDN) and cannabinoid products helpful.
Health Rising has done many blogs on low dose naltrexone – check out it’s Low Dose Naltrexone Resource Center for ME/CFS and Fibromyalgia

Low Dose Naltrexone (LDN) Fibromyalgia and Chronic Fatigue Syndrome Resource Center

Health Rising’s *Cannabis* Series for ME/CFS and FM

Health Rising has produced many blogs on *Cannabis* including a 4-part series of in-depth blogs on using *Cannabis* for pain relief, sleep and improved cognition.

Fibromyalgia and ME/CFS Cannabis Resource Center

Cognitive Impairment

People with ME/CFS and FM often suffer from cognitive impairment that can lead to brain fog, trouble with word finding and more debilitating symptoms. In this class, you will understand the types of cognitive issues that commonly occur, possible causes, and how to implement strategies to improve cognitive function.

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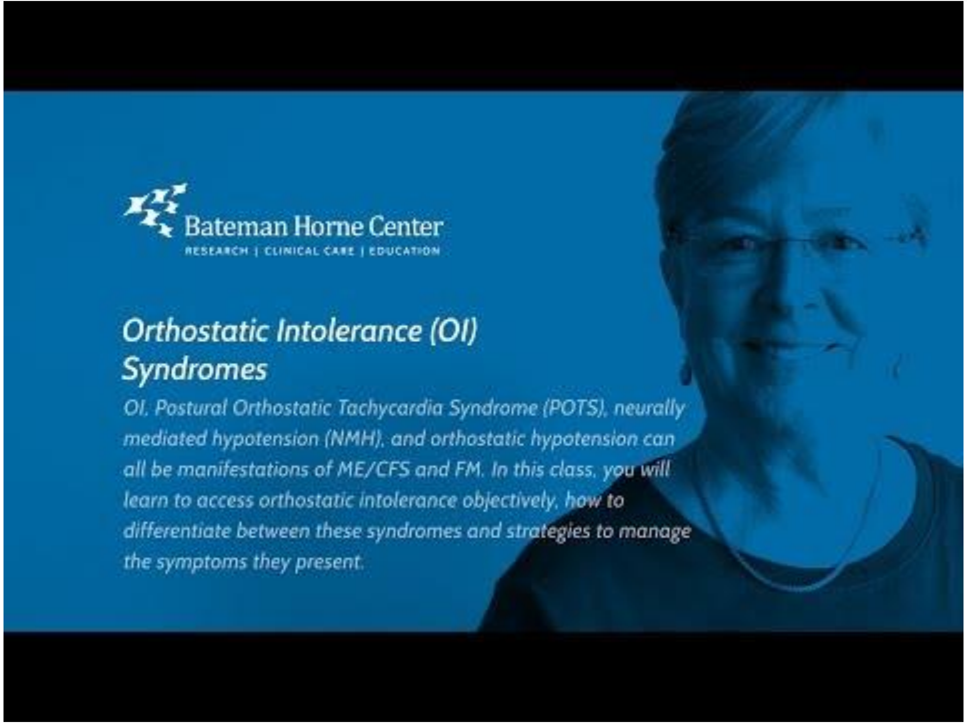
Orthostatic Intolerance (OI)

OI, Postural Orthostatic Tachycardia Syndrome (POTS), neurally mediated hypotension (NMH), and orthostatic hypotension can all be manifestations of ME/CFS and FM. In this class, you will learn to access orthostatic intolerance objectively, how to differentiate between these syndromes and strategies to manage the symptoms they present.



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Orthostatic Intolerance (OI) Syndromes

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Check out many resources on orthostatic intolerance in Health Rising's Resource section including: **Dr. Rowe's guide to treating it**, **a home test for orthostatic intolerance from the Bateman Horne Center,** **a home postural orthostatic tachycardia test**, **a great portable chair for shopping**, etc.

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  - Check out more **treatment resources here.**

How to Tell the Difference Between Depression and ME/CFS

Many doctors may confuse post COVID-19 illnesses or ME/CFS with depression. Depression/anxiety is a natural outcome of having a chronic illness and you may be depressed, but being depressed because of an illness is a far different thing than depression causing your illness. If you are depressed, get treated for it, but run from doctors who think all you have is depression.

How to Prove To Your Doctor That You're Not (Just) Depressed – Check out ways to convince your doctor that you're not just depressed.

Keep Track of Your Medication/Supplement Use with this interactive document produced from Kelly, a person with ME/CFS.

Exercise

Specialized exercise programs that have been designed for ME/CFS can help avoid deconditioning – which causes many problems on its own – and to stay as fit as possible and improve your quality of life.

Studies have shown that because many people with ME/CFS have broken aerobic energy production pathways, they tend to rely on anaerobic energy production pathways which produce toxic by-products that result in fatigue and pain.

These exercise protocols developed for ME/CFS use short exercise periods interspersed with rest which keep people safe. Some use heart rate monitors to keep your heart rate down. Many use recumbent exercises.

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    - Check out Health Rising's **many resources on exercise and ME/CFS**

Diet

While no one diet has been shown to work best for ME/CFS, general dietary guidelines have emerged. There are plenty of exceptions, but more people seem to do best with small, lower carbohydrate, and higher fat and protein meals. Morning fasts help some. One universal recommendation is to knock out sugar and processed foods.

Check out Health Rising's Diet resources including **How a FODMAPS diet may able to reduce pain**, **anti-inflammatory foods and diets**, how **we're wired to eat unhealthy foods,** (and how to discover what those are), **ketogenic diets** and more.

Increasing Blood Volume

Because people with ME/CFS can have very low blood volumes (no one knows why), increasing blood volume by drinking more liquids supplemented with salts, electrolytes, and special blood volume enhancers is often recommended.

- Check out Health Rising's page on **increasing your blood volume here**.

Other Treatment and Coping Basics

- **Treatment Resources** – check out over 250 ME/CFS and FM treatment resources on Health Rising.

Disability and Finances

Many state and federal programs – probably many more than you think – can help out with finances. Check out the amazing **How To Get On** website, put together by a person with ME/CFS, to learn about the many opportunities out there.

Disability

Few people anticipate or want to think about going on disability, but preparing for it, in case you have to go this route, can reap dividends. Keeping a daily or weekly journal that highlights your symptoms and, most importantly, your functional impairments – what you can do or can't do – can provide valuable evidence for your case. Using a Fitbit or similar tool to document your steps per day can help. Seeing your doctor regularly and emphasizing your functional impairments in the doctor's office is very important. Disability cases are not won on symptoms, but on documenting your inability to work; i.e. your functional status. Having your doctor regularly document your functional status can do wonders for your case.

Exercise testing – Two-day exercise tests can provide a kind of gold standard for disability evaluation. These tests – which involve two short maximal exercise tests, done a day apart, are one of the only ways to objectively document your functional status. They're very hard to beat in court. The **Workwell Foundation** in California has been providing disability evaluations using 2-day exercise tests for many years. They've reported that **90% of their clients** have received disability using their reports.

Guides to getting disability, focused specifically on ME/CFS, have been created.

How to Apply for Social Security Disability Benefits If You Have Chronic Fatigue Syndrome (CFS/CFIDS) – by Kenneth S. Casanova – available free from the Mass. CFIDS Association website. The best single resource on disability for ME/CFS.

Four-Part Series – Check out Cort Johnson's four-part series on Disability and Chronic Fatigue Syndrome (ME/CFS): **Disability I**/ **Getting the Diagnosis** / **Documenting Your Limitations** /**Resources.**

Check out **How To Get On –** a superb website featuring many articles on how to get help including how to get on disability. Check out many **more disability resources here**