



# The Solve CHRONICLE

SPECIAL RESOURCE EDITION

SUMMER 2023

## Navigating ME/CFS and Long Covid

Individuals navigating complex diseases such as ME/CFS and Long Covid are often charged with developing subject-matter expertise to advocate for themselves in healthcare spaces – all while managing their own symptoms and health.

This special edition of *The Chronicle* features key resources from our website that we hope community members can utilize as they navigate their own journeys with ME/CFS or Long Covid.

We'd like to offer special thanks to members of Solve's Lived Experience Task force (LET) – our community leadership partners – for their valuable feedback during the production of this *Chronicle*. LET insights are critical to improving our ability to deliver responsive services, programming, training and technical assistance to organizations and other partners

affected by these conditions. LET partners even selected the topic for our recent EmPOWER M.E. event for Advocacy Week 2023!

Although there aren't currently cures or FDA-approved treatments for ME/CFS or Long Covid, there are interventions and symptom-reduction strategies that individuals can use to significantly improve quality of life. Many of these resources were adapted or sourced from the work of Susan Rebecca Culbertson, MSW LISW, and all can be found on our website at [solveme.org](https://www.solveme.org).

*These resources are not intended to substitute individual, professional medical advice, diagnosis, or treatment. Please seek the advice of your medical provider before starting any new medication, treatment, or therapy. Solve M.E. cannot provide medical advice.*

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Solve M.E. | Making breakthroughs possible

# A Guide to Post-Exertional Malaise (PEM) and Rest

Post-Exertional Malaise (PEM) – the most devastating symptom of ME/CFS and Long Covid – is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.

With ME/CFS and Long Covid, quick, easy recovery cannot be taken for granted. Often crushing fatigue – even after minor everyday exertions – is a major concern.

PEM is the ongoing failure to recover. When people with ME/CFS or Long Covid attempt to exercise their way back to full strength or “push through” symptoms, the most common outcome is even longer and more severe periods of exhaustion, often referred to as “crashes.”

One of the great frustrations of those living with ME/CFS or Long Covid is that even the most ordinary daily tasks can trigger a severe PEM reaction. The mental exertion of reading instructions, studying, reading a good book or balancing a checkbook (or the computerized equivalent), can ignite an unexpected PEM response. Worry and stress can trigger PEM as well. Sudden fatigue to the point of exhaustion is even more frequent when dealing with common emotionally tense situations; disagreements between family members, financial demands, and a contentious political conversation are all possible scenarios that are likely to produce a “crash.”

PEM can be reasonably controlled by “activity management,” also called pacing, for daily activities, work, travel, or even holidays. Your main goal must be to avoid PEM flare-ups and illness relapses, by balancing your activity and rest.

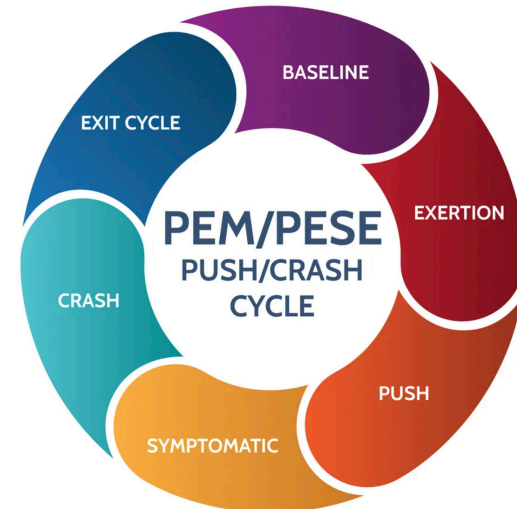
You can also take control of other environmental factors that can limit PEM.

## A Solve LET Member says...

“This guide to PEM and Pacing provides a concise resource for caregivers and patient alike to better understand the complexities of PEM. A good introduction for those newly diagnosed, or a reminder for those complex moments in the middle of PEM when one cannot recall anything that one has ever learned even after years of illness, this guide offers a quick reference.”



Photo: Lea Airing and German Association for ME/CFS



Graphic courtesy of Bateman Horne Center

## PACING AND RESTING

As a person with ME/CFS or Long Covid, you need to determine your individual limits for physical and mental activity, and plan your day accordingly. Through trial and error and tracking your symptoms after different types of activities, you can find your rhythm to avoid “crashes.”

Rest is the main ingredient for reinstating your physical equilibrium. Rest can be done prophylactically as a course of action to prevent PEM. Limitations may be different for each person, but by utilizing personal daily diaries and charting, you will be able to discover different patterns of symptom improvement and/or regression. With any chronic illness you need all the advantages you can garner to improve your daily life.

## PACING TACTICS

- **Prioritize your activities** and delay, delegate or eliminate non-essential items.
- **Minimize sustained physical or cognitive exertion** by dividing and spreading out your activities into small segments with planned rest periods in between. For moderate to severely ill patients, even normal activities of daily living (eating, bathing, dressing) should be modified to avoid triggering PEM.
- **Immediately stop and rest** if you start to feel dizzy or short-of-breath, notice your heart rate increasing, or sense other PEM warning signs that might be unique to you. Don't try to “push through” when you feel sick or tired. Although the concept is lauded in today's society, doing so with ME/CFS or Long Covid will only exacerbate your symptoms and potentially worsen your illness.
- **Schedule rest time** (even if you don't think you need it) to relax your body and allow for potential healing. When anticipating the need for extra energy (e.g. trip to the doctor, night out with friends, special occasion), plan extended rest time before and after the event.
- **Learn to recognize emotional PEM triggers** and take steps to avoid or minimize their impact. If a stressful situation is primarily beyond your control (e.g. the actions of others, world events, lack of understanding about this disease) try to take the emotion out of your thought process. Worrying or holding on to anger when you can't do anything about a situation rarely accomplishes anything for anyone, but if you're living with ME/CFS or Long Covid, it can use up your energy and cause you harm.
- Difficult as it may be, **avoid the temptation to do too much** when you're feeling a bit better. It is rarely worth the consequences when living with ME/CFS or Long Covid.

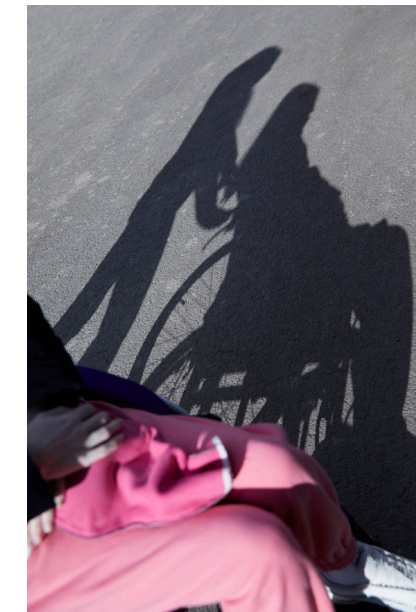


Photo: Sergej Preis and German Association for ME/CFS

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Each board member has a personal connection to post-infection diseases. They either themselves live with these diseases, have a loved one who suffers, or care for people who are impacted.

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# Tracking Your Symptoms

Keeping track of your symptoms through journaling or charting, especially early on, can help you identify your personal limitations and provide valuable data for your medical team. While illnesses such as ME/CFS and Long Covid can be unpredictable and come with many ups and downs, over time, you may be able to find recognizable patterns that can help you manage.

The symptoms of ME/CFS and Long Covid are many and varied. Symptoms may be constant, worse some days, better some days. Or, you may experience a symptom for a while, and then it may dissipate as a different symptom appears. This is part of the frustration for both persons with ME/CFS or Long Covid, and for physicians treating these illnesses. At right you will find a list of typical symptoms shared by many with ME/CFS or Long Covid. You may experience any of these at different times, in different ways, in different levels of severity.



Early charting can be focused on symptoms and their severity. As you get more comfortable with tracking your symptoms and experience, you may also want to record your medication, diet, stress level, and anything else that may impact your symptoms.

If your stamina is extremely limited, ask a friend or family member to assist with charting on days you are unable. On the difficult days, pitching in to keep the record clear and current is a valuable contribution a caregiver or family member can offer.

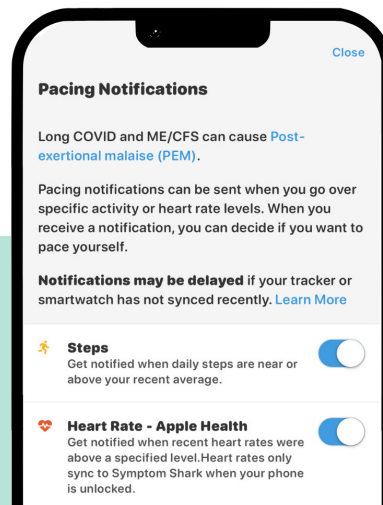
Beginning September 12, individuals seeking to track their symptoms can use Solve Together – our new patient-driven data platform – which also features pacing notifications! Join our newsletter to receive emails with links to join.

## SYMPTOM CHECKLIST



- Post-exertional malaise (PEM), the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks
- Non-restorative sleep/sleep disturbance
- Brain fog/cognitive impairment
- Joint pain
- Inflamed lymph nodes
- Persistent sore throat
- Severe headache
- Neurological abnormalities
- Complete organ system shutdown
- Sensitivity to light, sound, odors, chemicals, foods, and medications
- Persistent fatigue for six months or more
- Headaches
- Migraine
- Dizziness
- Muscle Pain
- Sore Throat
- Add other symptoms that are personal to you

To learn more and find examples of daily symptom logs, visit our Patient & Caregiver Resources at [solve.together.org](https://www.solve.together.org).



# Interviewing Your Potential Doctor

Your initial appointment with a physician can be treated like a job interview. Your care is personal and deeply important.

ME/CFS and Long Covid can often be frustrating and confusing diseases – both for patients and healthcare providers. Be upfront about your own expectations and concerns. Write your interview questions down. Keep your list of interview

questions as short as possible, without compromising your ability to make an informed decision.

Allow the doctor time to give thoughtful answers. Sort your most important questions to the top of the list, with the realization your session could be cut short by the physician being called to an emergency. And remember, you have every

right to expect any physician to give your concerns their genuine consideration. Be picky – you are making a serious decision.

If you are finding it difficult to locate any doctor in your area that is familiar with ME/CFS or Long Covid, your best choice may be to work with a doctor who is actively curious about you first, and the diseases second.

## INTERVIEW WORKSHEET

Practice Name: \_\_\_\_\_

Contact Information: \_\_\_\_\_

Date: \_\_\_\_\_

- |  |   |
|--|---|
| <p>1. Approximately how many patients have you treated with ME/CFS, Long Covid, or another infection-associated chronic illness?</p> | <p>4. Would you be willing to work in coordination with my other doctors?</p> |
| <p>2. What do you know about these diseases, and do you believe they are real and valid illnesses?</p>                               | <p>5. Add my own questions:</p>   |
| <p>3. Do you have a protocol for treating these diseases?</p>  | <p>6. My impressions:</p>   |

# Job Accommodations for People with ME/CFS & Long Covid



The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on job accommodations and disability employment issues. Serving customers across the United States and around the world for more than 35 years, JAN provides free one-on-one practical guidance and technical assistance on job accommodation solutions, Title I of the Americans with Disabilities Act (ADA) and related legislation, and self-employment and entrepreneurship options for people with disabilities. The following resources are sourced from [askjan.org](http://askjan.org) and can help employers accommodate individuals with diseases such as ME/CFS and Long Covid.

Employees with these diseases will experience varying degrees of limitation and will require varied accommodations.



## Questions to Consider:

1. What limitations is the employee experiencing?
2. How do these limitations affect the employee and the employee's job performance?
3. What specific job tasks are problematic as a result of these limitations?
4. What accommodations are available to reduce or eliminate these problems? Are all possible resources being used to determine possible accommodations?
5. Once accommodations are in place, would it be useful to meet with the employee to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed?
6. Do supervisory personnel and employees need training?

# There is No Time to Waste

Since the onset of the pandemic, the number of people suffering from ME/CFS has more than tripled and everything from requests for additional research grants to requests for additional patient resources have been pouring in.

As a nonprofit leader in this space for nearly 40 years, Solve M.E. is ready and determined to serve the needs of our growing population of patients and those who we know will find the cures.

"We need some sort of hope. And Solve has done that for so many of us."

— Allyson, ME/CFS Patient

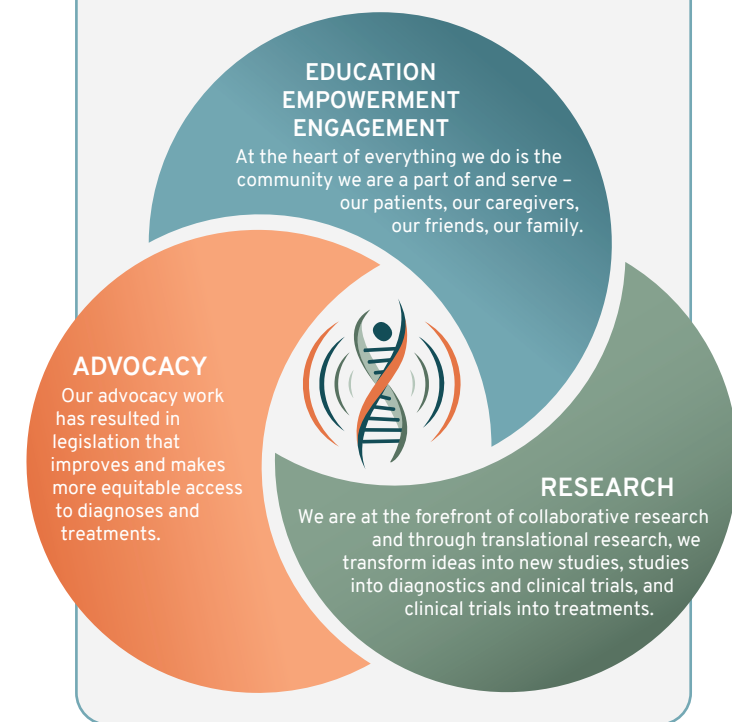
But we simply cannot do this work alone and when it comes to finding treatments, cures, and a better outlook for ME/CFS, Long Covid, and other post-infection related illnesses, there is no time to waste.

For too many of us, the struggle has been going on for years, even decades, and for those newer to our community, the pain is no less troubling. When we receive support from friends and allies like you, no one has to struggle alone, and providing hope can be met with providing solutions.

"Our organization is a catalyst and convener – one that can leverage its research and advocacy capabilities to end the suffering of the millions who suffer from ME/CFS, Long Covid, and other post-infection diseases."

— Oved Amitay, President & CEO, Solve M.E.

At Solve M.E., we know that to **Make Breakthroughs Possible**, our efforts need to be comprehensive.

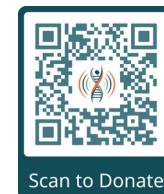


"What do people do when they don't have resources? What do patients experience when they don't have resources? The education, awareness, research that Solve provides is extremely important."

— Stewart, Father of patient with ME/CFS

**As our community grows, so does the impact of your support.**

Make a gift today using the QR code, online at [solveme.org/donate](http://solveme.org/donate), or call our Development team at 704-364-0016 ext. 207. Thank you!



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# On the Cusp of a Paradigm Shift

Dear friends,

Sometimes a slight tilt of the head is enough to bring about a dramatic shift in perspective – even if something may have been there all along. Sometimes people call such a change a paradigm shift, a rising of a new horizon. These moments don't happen very often, especially within the scientific disciplines. This summer, I have been fortunate enough to witness two of these rare, exciting moments.

A two-day meeting held by the National Academies of Sciences and Medicine (NASEM) in late June, "[Toward a Common Research Agenda in Infection-Associated Chronic Illnesses](#)," provided a unique opportunity for researchers, clinicians and patients to examine the common, overlapping clinical and biological factors of ME/CFS, Long Covid, and Lyme Disease. While these diseases are themselves heterogenous and may involve a variety of manifestations, the commonalities were striking.

The global COVID-19 pandemic highlighted how scientifically inadequate our understanding of these disease categories – which also include POTS, mast cell activation, and fibromyalgia, among others – is. There is so much to be learned from research in each of these respective areas to inform one another. We can make significant strides when tools, methods and fresh perspectives come together from these varied directions, approaching this broader field as a whole. The excitement in the NASEM meeting room was so palpable that even the participants on Zoom could feel it. From these meetings, a strong consensus emerged on the importance of bridging the clinical and scientific silos to get us closer to the answers and treatments that have eluded us for so long.

A similar movement is happening within the patient communities. Solve M.E., together with other leaders of the Long COVID Alliance – Dysautonomia International, COVID-19 Longhailer Advocacy Project and Patient-Led Research Collaborative – received an award from the CDC Foundation to explore the needs of a wider range of disease communities and the possibility of establishing a broader Patient Advocacy Coalition of Infection-Associated Chronic Conditions. While not all cases of ME/CFS or other diseases are clearly triggered by a known infection, this wider lens would nonetheless help to address these aspects as well. We were privileged to meet dozens of leaders from advocacy organization across this spectrum of diseases, including ME/CFS, Lyme Disease, Long Covid, Dysautonomia, PANDAS, Multiple Sclerosis, Mast Cell Activation and Autoimmune Diseases. We have been inspired by the level of engagement and commitment from these communities and will report on this effort at an [upcoming national webinar on October 24](#).

I believe that the combined voices of our patient communities, together with a more cohesive scientific community, will be powerful in bringing the recognition and resources to address our common needs: treatments, cures and policies that improve the daily lives of the people and families affected by ME/CFS, Long Covid, and associated conditions. We are closer to this long-awaited change than ever before.

Onward, with sincere hope,

*Oved Amitay*

Oved Amitay  
President & CEO,  
Solve M.E.



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