

Dealing with severe ME after COVID-19



LONG COVID ESSENTIALS: A series by [The Sick Times](#) & [Long COVID Justice](#)

Many people with Long COVID have symptoms of **myalgic encephalomyelitis (ME)**. ME is a [chronic disease](#) that involves debilitating fatigue, cognitive problems, sleep issues, pain and other symptoms, which worsen after activity. About one in four people with ME have severe/very severe disease; some with Long COVID experience similarly severe symptoms.

Definitions vary for severe / very severe ME. Generally, people with more severe symptoms spend most or all their time in bed, have difficulty leaving home and need help taking care of themselves.

- Movement is hard; people may need rest after just a few steps, if they are able to stand or walk at all.
- Concentration is difficult, and can only be done in short spells.
- Screens, reading, conversations, smells, sounds and/or lights may be overwhelming.
- Some develop new food allergies or intolerances.
- The most severe patients may be unable to handle touch, or eating (requiring liquid nutrition).

People with [severe ME](#) and those around them need to radically adjust their expectations for how much a body can do.

- Find your activity baseline – for example, 400 steps, or one hour of concentration each day. Adjust your expectations, and plan shortcuts to stay within or under your baseline. Learn to say ‘no.’
- Take many small breaks during activities.
- Eat small, nutritionally dense meals to reduce eating effort.
- Identify and remove any food sensitivities, environmental triggers, or other energy stealers.
- Mechanical assistance devices (grabber, scooter, wheelchair, stair lift, shower chair) can save you work.
- Work with your caregiver to choose strategies for easing [daily living](#) activities.



People with severe ME are often **left out of medical research**, and doctors may not know how to take care of them. It's especially important for you to seek a team of carers you can trust. You can task them with learning about the disease on your behalf, finding providers, coordinating your care, and advocating for your needs, to save you effort.

- Seek care in the home when possible, to avoid traveling to medical appointments.
- Very severe symptoms with trouble eating may be misdiagnosed as anorexia. Caregivers, [advocate](#) for your loved one and make sure they have the right diagnosis.
- In the U.S., you may be eligible for [disability coverage](#) through private insurance or the federal government.

* Resources

Definitions:

- [\[text\] Encyclopedia: Severe ME](#)
- [\[text\] Brochure: Severity in ME](#)

Patient explainers:

- [\[text\] What is severe ME?](#)
- [\[video\] What is Severe ME/CFS?](#)
- [\[text\] Challenges for patients with severe ME/CFS](#)

Patient experience:

- [\[text\] Whitney Dafoe](#)
- [\[video\] Diana Cowren](#)

Learning about care:

- [\[video\] Assembling a care team](#)
- [\[text for caregivers\] Supporting a person with ME](#)
- [\[text for caregivers\] Guide for severe ME caregivers](#)
- [\[text for practitioners\] Professionals supporting severe ME](#)



Clinical recommendations/information:

- *[text for caregivers and practitioners]* [Clinical care for severe ME, US CDC](#)
- *[text for caregivers and practitioners]* [Management guidelines to severe ME \(UK's NICE\)](#)
- *[text for practitioners]* [Clinical summary - ME/CFS clinical care](#)
- *[text for practitioners]* [Expert advice](#)

FULL SERIES OF FACTSHEETS WITH LINKED RESOURCES + MORE:

tiny.cc/LCE or scan the QR code with your phone camera



QUESTIONS? connect@s4hi.org

This series was designed by people living with Long COVID and associated diseases. Each resource sheet has been reviewed by patient and medical experts. This is an informational resource, not medical advice. Publication date: 12/13/2024.