

A Misunderstood Disabling Chronic Illness: How You Can Support Loved Ones Living with Long-COVID

Long-COVID Facts

Long-COVID is defined as experiencing long-term effects after an infection of COVID-19.

- Affects 1 in 5 adults who have had COVID-19 in the last year
- Impacts people of all ages regardless of their health status
- Is considered a disability under the ADA, Section 504, and Section 1557

Impact of Long-COVID

Long-COVID symptoms present differently for each person and occur with varying degrees of severity.

This condition often leads to a drastic change in ability to function, which can vary from day-to-day.

The symptoms are often unpredictable and can lead to feeling a loss of control while also trying to continue forward with their life.

The common symptoms and challenges are listed below, however, do not fully capture *all* Long-COVID experiences.

Common Symptoms

Common Challenges

Physical

Fatigue, body aches, pain, nausea, dizziness, vomiting, heart palpitations

Exacerbation of other medical conditions, decreased ability to be active, need for more breaks, need for more time to complete tasks

Cognitive

Brain fog, word finding and memory problems, difficulty concentrating

Difficulty scheduling and planning, forgetting conversations, needing reminders to complete tasks, slower talking, losing track of conversations

Emotional

Anxiety, depression, trauma, isolation, grief, identity changes, relationship distress

Increased sleeping, crying, isolation and self-criticism; not engaging in previously enjoyed activities, fear of leaving the house, changes in social engagement, becoming easily overwhelmed

Messages from People Living with Long-COVID

I'm doing the best I can to function and survive, even though:

I'm grieving the change in my health, ability to work, relationships, and future.

Long-COVID symptom variation prevents me from planning far in advance and having a consistent routine. That can feel overwhelming, chaotic, and dysfunctional.

Many of my Long-COVID symptoms are "invisible." Other people can't easily see them, but that doesn't make them any less real.

I don't know how I'll feel day to day, or moment to moment.

Managing physical symptoms is physically and emotionally taxing, which impacts my cognitive functioning and can impair my ability to advocate for appropriate care.

The unknown of Long-COVID is exhausting and frustrating. There is still a lot for everyone to learn and understand about Long-COVID.

How can I be supportive?

Practical and Physical

- Supporting loved ones with Long-COVID includes listening to what might be most helpful to them specifically. Each person has specific needs and knows themselves best.
- Remind your loved one to take breaks and rest regularly, and more as needed.
- Help your loved one with tasks that require significant time and energy.
- Assist with scheduling and helping your loved one get to healthcare appointments.
- Attend healthcare appointments with your loved one and take notes.
- Help advocate for their best interest and values and aim to be their voice when they are unable to speak up.
- Help your loved one find information about Long-COVID and understand new information as it becomes available.

Emotional

- Listen and validate your loved one's experience. Aim to be compassionate, understanding, and kind.
- Understand that your loved one might be easily overwhelmed and may not have the emotional capacity to take on additional stressors.
- Offer to do low-stress and enjoyable activities together, with flexibility for changing plans, postponing plans, and taking breaks. Ask your loved one what those activities might be for them.
- Encourage loved ones to engage in movement and stress management that works for them.
- Help them find additional avenues of social support, including groups, individual therapy, and ways to virtually connect with others.

Resources for More Information:

- <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/care-post-covid.html>
- <https://www.longcovidsos.org>
- <https://www.wearebodypolitic.com/covid-19>