

Caregivers: Supporting a Loved One with Long COVID

Understanding Long COVID as a Caregiver

Long COVID is a complex and fluctuating condition. Symptoms can include severe fatigue, brain fog, shortness of breath, pain and sensory sensitivity. These symptoms are often not visible and not predictable, which can make caregiving challenging.

It's important to remember that:

- Good days don't always mean recovery; symptoms can flare unexpectedly.
- Rest and pacing are not laziness, they are survival strategies.
- Emotional impacts (like grief, anxiety, or frustration) are normal on both sides.

Communication Strategies

- Listen without fixing- Sometimes your loved one just needs to vent. Avoid jumping into solutions right away.
- Ask what they need today- Their needs may shift daily depending on symptoms.
- Respect limits- Even "small" tasks like a short walk, loud conversation or running errands can cause symptom flares or feel like too much.
- Check in gently- Ask how you can best support them and keep communication open without judgment.

Practical Help

- Assist with daily tasks (grocery shopping, cleaning, childcare, driving).
- Help manage medical appointments or keep track of paperwork.
- Learn about crash planning and energy conservation so you can help protect their limited energy.
- Encourage rest and pacing, even if progress feels slow or inconsistent.

Emotional Support

- You are allowed to have feelings too- Anger, sadness and exhaustion are normal.
- Find your own support- Whether through friends, caregiver support groups or counseling.
- Prioritize your well-being- Burnout helps no one. Rest, set boundaries and make space for joy in your own life.

Navigating Boundaries and Safety Concerns

Many caregivers face extra challenges when their loved one is highly concerned about re-infection. You may be asked to wear a mask constantly, avoid group activities or change your usual routines.

While these concerns come from a place of real fear and vulnerability, they can sometimes leave you feeling restricted or isolated. Here's how to approach this with care and balance:

Acknowledge their fears as valid — Even if you don't feel the same level of concern, recognize that their anxiety is often driven by past experiences, medical vulnerability or trauma. Avoid dismissing or minimizing it.

Communicate openly about your own needs — You are allowed to want time with friends, social activities and outings outside the home. Explain that caring for your emotional well-being ultimately makes you a better and more present caregiver.

Work together on compromises — Can you agree on certain safety practices at home (like masking when you return from large events or testing if you feel unwell) without entirely giving up your own life? Shared agreements can ease anxiety on both sides.

Seek outside guidance if needed — Sometimes involving a counselor, support group or medical provider can help mediate these conversations, especially if tensions feel high or compromise feels impossible.

Remember: Balance matters — It's not selfish to protect your mental health and social connections. Finding a middle ground that honors both your loved one's safety concerns and your own autonomy is key for long-term sustainability.

Caregiver Resources

ARCH National Respite Network and Resource Center

Provides a national registry of respite programs and services to help caregivers find short-term relief and support, including for those caring for individuals with chronic illness or disabilities.

<https://arch.gnosishosting.net/Portal/Registry>

Caregiver Action Network

A national nonprofit organization providing free education, peer support, and resources for family caregivers across the United States, covering a wide range of caregiving situations.

<https://www.caregiveraction.org/>

Caring for People with Long COVID (CDC)

Provides guidance and resources for caregivers supporting individuals with Long COVID, including tips on communication, managing uncertainty, and accessing healthcare services.

<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/caregiving.html>

CaringInfo.org

Offers resources for caregivers navigating the legal and logistical challenges of severe illness, including palliative care, hospice, Medicare, insurance, advance directives, and bereavement care.

<https://www.caringinfo.org/Solve+ME/CFS+Initiative+1>

Cleveland Clinic – Caregiver Burnout

Offers a practical overview of caregiver burnout, including signs, symptoms, and tips for preventing and managing stress, fatigue, and emotional exhaustion in caregiving roles.

<https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout>

Family Caregiver Alliance

Provides information, education, services, and advocacy for caregivers, including resources on caregiver health, legal issues, and care planning.

<https://www.caregiver.org/>

How to Support Someone with Chronic Illness (Mayo Clinic)

Offers practical advice for friends and family on how to emotionally and practically support a loved one living with a chronic illness, including suggestions for meaningful conversations and self-care for caregivers.

<https://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/caregiver/art-20047235>

Long COVID Caregivers and Families (Long COVID Europe)

Provides advocacy, information, and resources specifically tailored to the needs of caregivers and family members supporting people with Long COVID, with a focus on European care systems but relevant insights globally.

<https://longcovid europe.org/long-covid-caregivers-and-families>

Long COVID Families

A patient-led advocacy group focused on supporting families affected by Long COVID, with special attention to children and caregivers, offering resources, community connection, and policy advocacy to improve care and outcomes.

<https://longcovidfamilies.org/>

Long COVID Kids

A UK-based charity advocating for families, children, and young people affected by Long COVID, providing support, raising awareness, and campaigning for research and policy changes.

<https://www.longcovidkids.org/>

Long-COVID Alliance – Caregiver Support

Offers resources for caregivers, including guidance on SSI/SSDI applications, mental health support, and webinars addressing the long-term effects of COVID-19 on children and families.

<https://longcovidalliance.org/category/caregiver-support/>

Loving Someone with ME/CFS or Long COVID (Solve ME/CFS Initiative)

A downloadable guide for families and caregivers supporting someone living with ME/CFS or Long COVID, offering advice on emotional support, communication, and managing the daily realities of chronic illness.

<https://solvecfs.org/wp-content/uploads/2022/05/Loving-Someone-with-MECFS-or-Long-Covid.pdf>

National Alliance for Caregiving

A nonprofit coalition dedicated to improving the lives of family caregivers and the people they care for. It works at the intersection of research, policy, and practice to advance support for informal caregivers across the United States. The organization produces evidence and insights on caregiving in the U.S., advocates for better systems and policies, and develops resources and tools that help caregivers understand and respond to caregiving challenges

<https://www.caregiving.org/>

National Institute on Aging (NIA) Caregiver's Handbook

A comprehensive handbook from the National Institutes of Health offering guidance on caring for an older adult, covering topics like daily care, medical management, long-distance caregiving, and self-care for caregivers.

https://order.nia.nih.gov/sites/default/files/2023-03/caregivers-handbook-nia_0.pdf

Patient and Caregiver Resources – Solve ME/CFS Initiative

Provides resources for people with ME/CFS, Long COVID, and caregivers, including symptom tracking tools, support system guidance, and information on navigating disability.

<https://solvecfs.org/me-cfs-long-covid/patient-and-caregiver-resources/>

Support Groups and Mental Health Resources – Long-COVID Alliance

Curated list of support groups and mental health resources to help patients and caregivers access community, advocacy, and emotional support.

<https://longcovidalliance.org/support-groups-and-mental-health-resources/>

Vanderbilt University – Long COVID Caregivers & Families

Provides resources to help caregivers learn about burnout, self-care, and where to find support, including links to caregiver action networks and handbooks.

<https://www.vanderbilt.edu/healthwellness/public-health/long-covid/long-covid-caregivers-families/>

“Stopping, calming, and resting are preconditions for healing. If we cannot stop, the course of our destruction will just continue. The world needs healing. Individuals, communities and nations need healing.”

-Thich Nhat Hanh

