

CAREGIVER RESOURCES

Caregiver's Companion Guide

Practical support for family members and caregivers of people living with Lyme disease.

You matter too. Caregiving is meaningful, demanding work. This guide is for you — not just the person you're supporting.

Understanding the Disease

Lyme disease can affect virtually every system in the body — joints, the nervous system, the heart, and more. Symptoms often fluctuate, meaning good days and very difficult days can alternate unpredictably. This is not your loved one performing wellness or illness — it is the nature of the disease.

- Fatigue may be severe and doesn't always respond to rest
- Brain fog (cognitive difficulties) is real and can be frightening
- Symptoms may shift in location and character from day to day
- The illness may not be visible to others, including some doctors

Communication That Helps

- Ask before advising: "Would you like to vent, or would you like help problem-solving?"
- Validate the invisible: "I believe you" may be the most important thing you can say
- Use person-first language: "my partner who has Lyme" not "my Lyme partner"
- Accompany them to appointments and take notes — a second set of ears matters
- Don't minimize or compare: "At least it's not cancer" is not helpful

Practical Support Checklist

- Help research providers using credible sources (projectlyme.org, CDC, major medical centers)
- Assist with insurance claims, prior authorizations, and appeal letters
- Help organize and transport medical records to appointments
- Take over household tasks during acute episodes without making it a burden
- Help children in the household understand what's happening in age-appropriate ways
- Manage medication schedules and pharmacy pickups

- Document symptom patterns to support medical appointments

Preventing Caregiver Burnout

Signs of burnout to watch for: Exhaustion that rest doesn't resolve. Resentment or detachment. Difficulty finding joy. Neglecting your own health. If you recognize these, take them seriously.

- Set realistic boundaries — and communicate them with compassion
- Accept help from others. You do not have to do this alone.
- Maintain your own health appointments, sleep, and social connections
- Consider speaking with a therapist who understands chronic illness caregiving
- Connect with other caregivers — community stories at projectlyme.org

My Support Network

People I can call when I need a break or support:

If you are in crisis, please call or text **988** (Suicide & Crisis Lifeline) or text HOME to 741741 (Crisis Text Line).