

Where to get help for Long COVID



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

If you suspect that symptoms you're experiencing could be related to Long COVID and you're trying to figure out where to turn next, help can be found in many places: from Long COVID clinics to primary care providers (PCPs) to support groups.

* **Start with your PCP, if you have one.**

- While many PCPs might not be familiar with Long COVID, some may be willing to help diagnose related conditions like [dysautonomia](#) or [heart problems](#). A PCP can also check for and rule out other conditions that might mimic Long COVID.
- Your PCP may be able to offer [treatments that improve symptoms](#).
- Some patients have found that [educating their PCP on Long COVID](#) and working with them to manage symptoms is easier than finding specialists. Many, but not all, PCPs are willing to learn from their patients. There are also new programs that are trying to [educate the healthcare workforce](#) about Long COVID.
- If you find you are not getting what you need from your PCP, consider other options.

* **Ask your PCP for a referral to a long covid clinic.**

- Long COVID and Post-COVID clinics have experience treating the disease. For example, the [Long COVID Care Network](#) is a government-sponsored initiative to expand access to Long COVID care in the U.S.
- There are also many clinics separate from the established networks. This [directory of Long COVID clinics](#) can help you get started.
- If possible, talk with others who have experience with different clinics or specialists before choosing where to go.



- If there are no established clinics in your area, you may want to consider a telehealth clinic. [RTHM](#) is one example of a telehealth clinic specializing in Long COVID.

Some patients have found solace and comfort by receiving support from others also living with Long COVID, online, and through support groups.

* Utilizing support groups and tools:

- [Long COVID Alliance](#) and [Long COVID Justice](#) both have support group directories and resources.
- There are many digital support groups and other resources for other diagnoses like [Myalgic Encephalomyelitis \(ME\) and dysautonomia](#).
- There are apps like [Refresh](#), where folks can meet other people with Long COVID to make friends with virtually (as a secondary form of support, if desired).
- There are also platforms like [Turnto Long COVID and NURA Community](#), which provide resources and connections.

* You may be eligible for disability benefits.

- Applying for disability benefits can be a stressful and confusing process to navigate. [Read this explanation of Long COVID as a Disability](#) Under the ADA, Section 504, and Section 1557 to understand your rights.
- Learn about the process of applying [from this blog](#) and [How To Get On](#), a site made by disabled people for those who need life hacks when learning to navigate disability.
- If you are still working, look into [paid medical leave](#) and [workplace accommodations](#).

* What to do while waiting for help:

- [Track your symptoms](#) using a journal, app like Visible, or a wearable. Medical practitioners often ask you to track your symptoms in a detailed manner; starting before an appointment can give you a head start.



- If you're waiting for an appointment with a clinic or specialist, [Long COVID Justice](#) provides a page full of medical, self-care and other resources.
- Consider if you'd like to join a [Long COVID study](#). Learn more about [reading scientific papers and participating in research here](#). Note that studies do not provide care.
- Some clinics or providers charge a lot of money for Long COVID care. Some patients benefit and others may not. From time to time, ask yourself whether you think you are benefitting from the care you are receiving. Feel empowered to make a change if you are not.

* Resources:

- [Directory of Long COVID Clinics](#) – Long COVID Alliance
- [Support groups list](#) – Long COVID Justice
- [Long COVID clinical trials](#) – Long COVID Studies

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.