

How to talk to healthcare providers about 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, here are some tips on how to navigate it within the medical system.

* **Starting the conversation**

- Ask the provider about their existing knowledge or understanding of Long COVID. Do they understand the seriousness? Have they worked with patients with similar experiences before?
- Assess whether they are empathetic and listen to you as an expert of your own experience. Do they seem willing to listen to you and trust your expertise?
- Start by listing symptoms, starting with two or three that have the most impact on your day-to-day life. [Bring your symptom journal or tracker](#) so you can share how symptoms are impacting you.
- You can provide studies or any [affirming evidence](#) you've collected, including [fact sheets from this resource series](#). However, it can be good to limit the amount of information you are offering, in order to not overwhelm the provider or use up too much time. Some providers may be resistant to outside information.
- If your primary care provider isn't helpful and you have concerning symptoms, consider finding a specialist or going to a [Long COVID clinic](#).

* **How to support someone else at the doctor**

- If you yourself are not experiencing symptoms related to Long COVID but wish to be a Long COVID advocate for someone, you can accompany them. People with Long COVID can also advocate for each other, if they have the energy and do not find it overwhelming.



- Advocates can help prepare for the appointment, provide transportation, witness the experience, vouch for their symptoms, help them document the appointment, and put pressure on providers to give care and take the patient seriously.

* **Medical gaslighting**

Medical gaslighting is when healthcare providers try to [convince someone they're wrong](#) about their own body or experience. It's most likely to happen to those most vulnerable to medical bias, including women, BIPOC, queer and trans people. It has been common among people experiencing Long COVID symptoms.

- Medical gaslighting can look like:
 - A provider minimizing or dismissing symptoms;
 - A provider refusing to order tests or refer you to a specialist;
 - A provider claiming your symptoms are “anxiety” or stress.
- If you're experiencing medical gaslighting, you don't have to accept it. You can get a patient advocate to come with you or call healthcare providers on your behalf. And you can seek a second, third, or fourth opinion from other providers.
- You are also legally allowed to record your appointment. A free app like [Otter.ai](#) can make a recording and transcript at the same time, using your smartphone.
- Long COVID specialist Dr. David Putrino offers questions you can ask and actions you can take if you experience medical gaslighting [in this video](#) (start at 56 mins).
- If you need to seek help for the mental and emotional impact of medical trauma or gaslighting, here's a [list of COVID-Conscious/affirming therapists](#).

* **Where to go if a provider doesn't help**

[See our resource on where to get help for Long COVID.](#)



* Resources

- [Healthcare appointment checklist for Long COVID](#) - CDC
- [How to deal with medical gaslighting](#) – *Psychology Today*
- [Directory of Long COVID clinics](#) – Long COVID Alliance
- [Lists of Long COVID support groups, online communities, and healthcare providers](#) – Long COVID Justice
- [Presentation about requesting Americans with Disabilities Act \(ADA\) accommodations](#) – Vermont Center for Independent Living
- [Paper about medical gaslighting with Long COVID](#) – *Qualitative Research in Health*

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.