

Getting Long COVID care when you are living with HIV



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

COVID-19 can cause short-term and long-term complications for people living with HIV. In fact, several studies have shown that people living with HIV are [more likely to experience Long COVID](#). When you have Long COVID, you may have challenges for navigating and advocating for care. This can include dealing with healthcare providers who might not know much about Long COVID or who may not believe your lived experiences.

Because some HIV providers may not be well informed about Long COVID due to stigma around the disease, it can be challenging to get proper care. Here are some tips on advocating for yourself, navigating discussions about COVID-19 and Long COVID with HIV providers, and dealing with medical trauma.

* **Where people with HIV can find care for Long COVID**

Often the best place to start seeking care for Long COVID is with your HIV provider. First, tell them you have been experiencing symptoms of Long COVID after a confirmed or suspected case of COVID-19.

[Detail what symptoms](#) you've been experiencing since COVID-19 and how they impact your quality of life. Try to distinguish the symptoms you think may be from Long COVID from any symptoms you typically experienced before you had COVID-19. However, if you had prior symptoms that are now worse after COVID-19, you can mention them, too.

While talking with your providers, you may realize they aren't aware of Long COVID. You can ask if they'd be willing to learn more, and would be willing to read more studies or resources about it for your next appointment.

As you navigate your search for care, remember that **you know your body best**. Trust yourself and the validity of your experiences.



* **Sharing information about Long COVID with HIV providers**

Sharing [large reviews like this one](#) about Long COVID can help educate your provider on Long COVID and associated conditions. Mentioning studies about why people with HIV are at higher risk for Long COVID, like [this study about the immune response to COVID-19 in people with HIV](#), may help them understand the overlap.

If your provider won't listen, you may also be able to seek care from another HIV medical provider or ask for a referral for a chronic disease management specialist. Ask other friends and people in your community if their HIV provider knows about Long COVID or if there are open-minded providers who are willing to learn more.

When making an appointment to see your provider, ask to have noted in your chart that you would like the provider to wear a KN95 or N95 mask to protect you from COVID-19 and other diseases. You can wear one to better protect yourself, too. You can also ask for an appointment to be telehealth so you can remain at home and meet with your provider on video.

* **Seeking further Long COVID care**

If your provider doesn't seem willing to learn about or take Long COVID seriously, ask them for a referral to a [Long COVID clinic](#) or a medical provider who is aware of Long COVID and related diagnoses like dysautonomia, myalgic encephalomyelitis (ME), and mast cell activation syndrome (MCAS). It can also help to bring a family member or friend to appointments to help you advocate for yourself, as well as a list of questions you have about the overlap of HIV and Long COVID.

* **Navigating medical gaslighting and trauma**

Navigating the healthcare system with HIV and Long COVID can be exhausting, overwhelming, and confusing, especially when [dealing with medical gaslighting](#) and medical trauma.

Being diagnosed with Long COVID or COVID-19 complications in addition to having an HIV diagnosis can be re-traumatizing and stigmatizing. You can talk to your loved ones, a [trained mental health professional](#), or community members about processing your



trauma – Long COVID and HIV support groups may be a helpful tool for connecting with others who have had similar experiences.

* **Additional resources:**

- [HIV and Long COVID](#) – Long COVID Justice
- [COVID-19 and people with HIV](#) – HIV.gov
- [Healthcare appointment checklist for Long COVID](#) – CDC
- [Healing medical trauma](#) – Psychology Today
- [What to do about medical gaslighting](#) – Harvard Health
- [Long COVID support groups](#) – Long COVID Justice

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.