When Long COVID sends you to the hospital



LONG COVID ESSENTIALS: A series by <u>The Sick Times</u> & <u>Long COVID Justice</u>

<u>Symptoms</u> associated with Long COVID can be unpredictable. It's not always possible to schedule a timely visit with your primary care provider if symptoms suddenly get worse. When that happens, there are other options for accessing treatment.

* ERs, urgent care centers, and walk-in clinics

- Emergency rooms are equipped to treat life-threatening conditions. People presenting with the most dire symptoms are seen first.
- Urgent care centers treat timely, but non-life-threatening symptoms. They serve
 patients in the order they arrive at the clinic. These centers usually have at least one
 doctor on staff and often have more advanced capabilities.
- Walk-in clinics also treat timely, but non-life-threatening symptoms. They usually have nurses and physician assistants on staff.

* Determining the type of care you need

When in doubt, don't hesitate to call 911. If expected symptoms become significantly worse, that may be a sign to seek emergency care.

Symptoms that <u>may require treatment at the ER</u> include:

- Sudden confusion or disorientation
- Feeling excessively sleepy to the point that others have trouble waking you up
- Blue lips, skin, or nails
- High fever (over 103°F)
- New onset chest or abdominal pain



- Trouble breathing
- Heart palpitations
- Sudden or unexpected headaches or dizziness

* Keep yourself safe during your visit

- Wear a mask: To avoid aggravating symptoms or exposing yourself to infections, including COVID-19, consider wearing an N95 mask.
- Ask providers to mask: Each healthcare setting will have a different policy, but if you feel safe doing so, it is acceptable for you to ask healthcare staff to mask as well.
- Ensure you are up-to-date on vaccines.
- Prepare a "go bag" ahead of time. This should include essentials for an unplanned or prolonged stay, such as a portable HEPA filter, an oral wash with cetylpyridinium chloride (CPC), water, snacks, charging cables, earplugs, sunglasses or an eye mask, a change of clothes, comfortable shoes, slippers, or flip-flops, and extra doses of medication in their original container.

* Advocating for your care

Medical professionals are often required to see as many patients as possible or are limited in the amount of time they can spend with a patient. They may struggle to give you the time and attention you need.

To make the most of your visit and avoid medical gaslighting:

- Highlight the symptoms that are bothering you most. Rather than trying to be exhaustive, set an "agenda" to focus on 2-3 key issues. The provider will likely appreciate this and be able to deliver higher-quality care during the visit.
- You may bring any log you have of your symptoms, especially the ones that are the reason for this visit. <u>Learn more about how and why to track symptoms here.</u>



- Keep an up-to-date medication list in your wallet or on your phone. Include any
 medications you are taking, including over-the-counter or complementary/alternative
 medications. Note the drug name, dose (for example, 50mg), and frequency (for
 example, once a day). Show it to the provider or give them a physical copy. This will
 save time, and will allow them to focus more on you and your symptoms.
- If you are not worried about an emergency, schedule a telehealth consultation. If you
 must go in person, it is okay to ask your doctor to reduce sensory stimuli such as
 bright lights, loud noises, or strong odors or to provide eye masks and ear plugs.
- Bring a support person, if possible.
- Record or otherwise document your time at the clinic or ER. This can mean taking notes or recording audio on your phone or requesting a notetaker.
- Carry communication cards or other resources to share with clinicians.

*** Resources:**

- Patient resources for navigating the healthcare system Bateman Horne Center
- <u>Tips for surviving a hospital trip when chronically ill</u> The Disabled Ginger
- The Long COVID Survival Guide, book with tips for confronting gaslighting
- Healthcare Appointment Checklist, steps for before, during, and after a visit CDC
- For clinicians treating people with Myalgic Encephalomyelitis (ME) ME Association
- <u>Tips for avoiding new infections in healthcare settings</u> CDC

FULL SERIES OF FACTSHEETS WITH LINKED RESOURCES + MORE: tiny.cc/LCE or scan the QR code with your phone camera.



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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.