

FREQUENTLY ASKED QUESTIONS: “LONG HAUL SYNDROME”

Graphic Design by Tanya Gale, BYU Department of Public Health

WHAT IS COVID-19 LONG HAUL SYNDROME?

After getting COVID-19, recovering from the viral infection, or even testing negative for the virus, some people continue to have COVID-19-related symptoms for several weeks or months or develop new COVID-19-related symptoms. We call this COVID-19 long haul syndrome, post-acute COVID-19 syndrome, or long COVID.

HOW COMMON IS COVID-19 LONG HAUL SYNDROME?

COVID-19 long haul syndrome appears to be quite common, but we do not yet know how common. Estimates from different studies range from 10% of COVID-19 patients to over 80% of COVID-19 patients have persistent symptoms several weeks to months after their initial infection. (Refs 1-7)

WHAT TREATMENTS ARE AVAILABLE FOR COVID-19 LONG HAUL SYNDROME?

At present, there are no standard treatments for COVID-19 long haul syndrome. (Refs 8-9)

WILL PEOPLE BELIEVE THAT I AM STILL SICK?

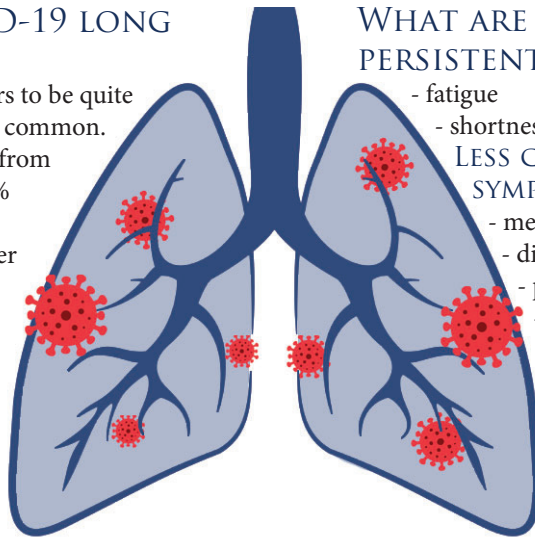
In early 2020, COVID-19 long haul syndrome was not widely recognized as a legitimate condition. This lack of awareness and understanding led to gaslighting of many early COVID-19 long haul patients by family members, friends, employers, and doctors, who did not believe that the persistent symptoms could be real. (Ref 10) This is likely still occurring. However, as information has emerged over the past several months about people who experience persistent symptoms, COVID-19 long haul syndrome is becoming better recognized in the medical community and in the public as a valid condition that warrants appropriate consideration.

WHERE CAN I LOOK FOR SUPPORT?

Grassroots online support groups allow people to connect with others to discuss their experiences with COVID-19 long haul syndrome, for example <https://www.facebook.com/groups/COVIDLongHaulers/> and <https://www.wearebodypolitic.com/covid19>.

For More Information:

1. Carvalho-Schneider C, et al. Clin Microbiol Infect. 2020 Oct 5. <https://pubmed.ncbi.nlm.nih.gov/33031948/>
2. Garrigues E, et al. J Infect. 2020 Dec. <https://pubmed.ncbi.nlm.nih.gov/32853602/>
3. Carfi A, et al. JAMA. 2020 Aug 11. <https://pubmed.ncbi.nlm.nih.gov/32644129/>
4. Halpin SJ, et al. J Med Virol. 2020 Jul 30. <https://pubmed.ncbi.nlm.nih.gov/32729939/>
5. Infectious Disease Society. 2020 Nov 19. <https://www.idsociety.org/covid-19-real-time-learning-network/disease-manifestations--complications/post-covid-syndrome/>
6. Tenforde MW, et al. MMWR. 2020 Jul 31. <https://pubmed.ncbi.nlm.nih.gov/32730238/>
7. Greenhalgh T, et al. BMJ. 2020 Aug 11. <https://pubmed.ncbi.nlm.nih.gov/32784198/>
8. NIH COVID-19 Treatment Guidelines, Clinical Spectrum. 2020 Dec 17. <https://www.covid19treatmentguidelines.nih.gov/overview/clinical-spectrum/>
9. Marshall M. Nature. 2020 Sep. <https://pubmed.ncbi.nlm.nih.gov/32929257/>
10. Yong E. The Atlantic. 2020 Aug 19. <https://www.theatlantic.com/health/archive/2020/08/long-haulers-covid-19-recognition-support-groups-symptoms/615382/>



WHAT ARE THE MOST COMMON PERSISTENT SYMPTOMS?

- fatigue
- shortness of breath or difficulty breathing

LESS COMMONLY REPORTED PERSISTENT SYMPTOMS INCLUDE:

- memory loss
- difficulty concentrating
- psychological distress
- trouble sleeping
- joint pain
- chest pain
- loss of smell and taste

(based on 4 studies of hospitalized patients in Europe (totaling about 500 people), the most common persistent symptoms of people reported 2-3 month after their initial illness (Refs 1-4, which were summarized in Ref 5)