Long COVID: An Overview

Lisa McCorkell
Patient-Led Research Collaborative
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- Team of Long COVID patients, non-hierarchically led by 5 women, majority POC
- Multidisciplinary team
  - Backgrounds in participatory design, neuroscience, public policy, data collection and analysis, human-centered design, health activism
- Formed out of the Body Politic COVID-19 Support Group on Slack

Check out this article for more on our story!
First Report on Long COVID

What Does COVID-19 Recovery Actually Look Like?
An Analysis of the Prolonged COVID-19 Symptoms Survey by

Patient-Led Research Team

Generated from survey data organized by decentralized team of COVID-19 patients,
exported on May 2, 2020 (640 Responses)

Report Released: May 11th, 2020 by
https://patientresearchcovid19.com

Report created and written by volunteers from the COVID-19 Body Politic Slack Group
Including: Gina Assaf, Hannah Davis, Lisa McCorkell, Hannah Weil, O’Neil Brooke, Athena
Akrami, Ryan Low, Jared Mercier, and Adetutu A.

Survey Authors and Contributors Include: Gina Assaf, Tine L., Annie C., Monica S., Jared
Mercier, Lauren N., Noel H., JD Davids, and Susie.

COVID-19 Can Last for Several Months
The disease’s “long-haulers” have endured relentless waves of debilitating symptoms—and disbelief from doctors and friends.
theatlantic.com

Practice ➤ Practice Pointer

Management of post-acute covid-19 in primary care

BMJ 2020:370 doi: https://doi.org/10.1136/bmj.m3026 (Published 11 August 2020)
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Research Paper

Characterizing long COVID in an international cohort: 7 months of symptoms and their impact

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https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext
What is Long COVID?

a.k.a. Post COVID-19 condition, Post-Acute Sequelae of SARS-CoV-2, PASC

“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.”
Symptoms

- **Over 200 symptoms** ranging all body systems

- **Top 3 symptoms:**
  - Fatigue
  - Post-exertional malaise (worsening of symptoms following any type of exertion 12-48 hours after)
  - Cognitive dysfunction (“brain fog”)

- Onset and timecourse of symptoms varies across individuals and by type of symptom
  - Neurological symptoms in particular tend to have a delayed onset

- 85.9% experience relapses with common triggers being activity, stress, menstruation
## 10 categories

1. Systemic
2. Gastrointestinal
3. Pulmonary
4. Dermatologic
5. Immunologic/Autoimmune
6. Cardiovascular
7. Musculoskeletal
8. Reproductive/Genitourinary/Endocrine
9. HEENT (Head, Ears, Eyes, Nose, Throat)
10. Neurological
Neuro: 9 subsections

1. Sensorimotor
2. Cognitive Functioning
3. Sleep
4. Taste and Smell
5. Speech and Language
6. Headaches
7. Memory
8. Hallucinations
9. Mood
Impact on work

- 67.5% had their work affected due to their illness
  - 45.2% required a reduced work schedule
  - 22.3% were not working at all

- Of patients with brain fog, 86.2% are mildly to severely unable to work because of brain fog.

- For those granted the option, teleworking, flextime, moving to a role with lower physical or mental strain, and other accommodations enabled them to continue working.

- Brookings estimates that 15% of unfilled jobs are due to Long COVID

“Haven’t been able to work for […] months due to brain fog. *Was supposed to go back last week on reduced hours. I resigned instead.* I have worked there as Director of […] for just over […] years.”

“Still on medical leave. Unpaid and *denied short term disability.*”

“While I’ve been able to keep my job while working from home, I must admit that if it were not so, I would most definitely NOT be able to work at all. *I can barely leave my bedroom on most days.*”
Common Diagnoses

● Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) - about half
● Postural orthostatic tachycardia syndrome (POTS) - about 2/3
● Mast cell activation syndrome
● Small fiber neuropathy
● Ehlers-Danlos Syndrome
How prevalent is Long COVID?

- 10-30% of non-hospitalized cases
- 50-70% of hospitalized cases

Household Pulse Survey estimates 7.6% of all US adults currently have Long COVID → 19 million+ people

Vaccination provides some protection, but not full:
- Between 15-50% protection, meaning 9-15% of vaccinated cases result in Long COVID
Resources

PLRC: http://patientledresearch.com/


Body Politic YouTube Channel: https://www.youtube.com/channel/UCuMpekylMvYax3mCk9Cwx4g


How to Get On (guide for disability benefits and accommodations): https://howtogeton.wordpress.com/

Twitter: @patientled, @ahandvanish, #LongCovid
Thank You!

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