



Community Support for Long COVID

This list was prepared by the team at Body Politic. Our mission is to break down barriers to care, particularly for marginalized communities by facilitating peer-support, public education, and leading community-based advocacy with a global network of COVID-19 patients, chronic illness allies, and disability advocates. We encourage people with Long COVID to join several groups to find the right fit. Every group listed below is patient-led, which means that patients lead the groups and help moderate them. Each group was also vetted by our team personally.

NEW HEALTH



New Health

@newhealthapp

A custom-built app for peer support launching summer 2023. Previously, Body Politic housed the first COVID support group in March 2020, which shut down in May 2023 due to lack of funding. A former Body Politic support group member and long-hauler co-founded the tech startup New Health to build a peer support app with the features and privacy control social media-based groups can't offer. The app is launching summer 2023, is open to anyone with prior COVID-19 infection and their caretakers, and will also have built-in health management tools with special features for flare-ups.

Subgroups: Tags for symptoms, demographics & more

BLACK COVID-19 SURVIVORS



Black COVID-19 Survivors

A private Facebook group for Black COVID-19 survivors. From the group: "Black and African-American people have been hard hit by the COVID-19 pandemic during a time when we already face medical inequality and bias in diagnosis and treatment. Come share your story, your family's story and let's talk out what's needed for recovery and reducing the spread."

Technological difficulty: easy

Size: medium (1,700+ people)

#ME ACTION



#ME Action

@MEActNet

Offering a variety of private Facebook support groups for Long COVID and ME/CFS. ME/CFS stands for myalgic encephalomyelitis, also called chronic fatigue syndrome.

Subgroups: support groups for Long COVID and ME/CFS, state chapters for location-specific support & activism, pregnancy and parenting with ME/CFS, caregiver support group, military & veteran families

Size: small to medium

Technological difficulty: easy

DYSAUTONOMIA INTERNATIONAL



Dysautonomia International

@Dysautonomia

Offering a variety of private Facebook support groups for people with autonomic nervous system disorders. Dysautonomia can be common in people with Long COVID or ME/CFS. (POTS is a common type, but not the only type of dysautonomia.)

Subgroups: Facebook groups for all US states, as well as specific support groups for teens, college, LGBTQ+, Black community, and men

Size: medium

Technological difficulty: easy

COVID-19 LONGHAULER ADVOCACY PROJECT



Advocacy Project

@C19LH_Advocacy

Offering a variety of private Facebook groups to create a space for advocacy, education and support for people with Long COVID. This group is led by a former paramedic firefighter who got COVID in March 2020. A great space to get involved with activism. State chapters also offer small support groups to help you find resources in your area.

Subgroups: Small Facebook groups for US states

Technological difficulty: easy

Size: medium (state chapters: small)

LONG COVID SUPPORT - FACEBOOK



Long COVID Facebook Group

@long_covid

A large (50k+) private Facebook group offering support for Long COVID with international reach. This is a private group for people with Long Covid or people who are caring for someone with Long Covid.

Subgroups: none

Technological difficulty: easy to moderate, due to size

Size: very large (50k+)

LONG COVID FAMILIES



Long COVID Families

@LongCovidFam

Peer support & workshops for caregivers, children, & individuals with long-term complications from COVID-19. Spanish language support (particularly for teens and school accommodation support) in progress -- please check website. Also offers guidance on accommodations at school & work

Subgroups: Spanish groups to come in the future (check the website)

Technological difficulty: easy

Size: small (100+ people)

BATEMAN HORNE CENTER



Bateman Horne Center

@BatemanHorne

Twice monthly support zooms facilitated by professionals, second and third Tuesday of each month 12-1:00pm PT. For individuals with ME/CFS, Long COVID, fibromyalgia, dysautonomia and related chronic illnesses. As well as family members, friends, and care partners.

Subgroups: none

Technological difficulty: easy

Size: small

QR code instructions: to use the QR codes (the black and white squares) to get the link for a support group, open the camera on your phone and point it at the square you want to get the link for. It should automatically recognize the link, and allow you to click to take you right to the website. If it doesn't scan, you can download a free QR code scanner like Google Lens.