



# 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 or a strong ally of patient-led groups, and was vetted personally by our team for appropriate moderation practices and group policies, as well as quality Long COVID information access.

## THE MIGHTY



The Mighty

@themightysite

A comprehensive non-social media platform for facilitating peer support across many different topics. They offer a large COVID-19 specific group (~20k members) and a small Long COVID group, in addition to many other communities available on the platform.

**Subgroups:** Hundreds of different subgroups based on shared identities, interests, hobbies; specific medical conditions, mental health conditions, general chronic illness & disability groups  
**Technological difficulty:** medium to difficult  
**Size:** Varies significantly by subgroup (<100 to 50k)

## 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



Covid-19 Longhailer 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

Their mission is to help the Long Covid community discover practical ways to enjoy life while impacted by chronic illness. They offer peer support and extensive informational resources for people impacted by Long COVID.

**Subgroups:** none  
**Technological difficulty:** easy  
**Size:** small (600+ people)  
**Tip:** website is a great resource for daily tips & symptom management

## BATEMAN HORNE CENTER



Bateman Horne Center

@BatemanHorne

Twice monthly support zooms facilitated by professionals on the 2nd & 3rd Tuesday of each month, 12-1pm PT. For people 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  
**Tip:** website is a great resource for symptom management & provider information

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.