

## Support Group Recap

### Navigating the Complex Healthcare Industry: Using Awareness and Self-advocacy Skills to Get What We Need

March 19, 2024

#### Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
  - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is still recruiting for two Long Covid studies. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.
- Latest newsletter: <https://batemanhornecenter.org/wp-content/uploads/2024/03/Winter-2024-newsletter.pdf>

*The following resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance nor endorsement.*

Timothy Weymann, LCSW introduced the topic by saying that one of the most common complaints he hears from people who are ill are related to the relationships they have with medical providers and interactions within the healthcare system.

#### Timothy's Shared Wisdom

- Self-awareness is fundamental to self-advocacy. We must be aware of ourselves and our own needs and wants to self-advocate and express hope and pursue those.
- A way to compensate for the challenge of finding informed healthcare providers is to find a collaborative doctor. When Timothy was first sick with his chronic illness, he had an amazing doctor who was humble and collaborative and willing to learn about Timothy's situation. Timothy was also empowered to learn as much as he could about his own illness. This allowed Timothy to self-advocate with his providers by saying "Hey let's try this. Or what about this? Or have you heard about that?"
- Remember that medical professionals and healthcare facilities are governed by an organized oversight body within each state in the U.S. That oversight body is there to protect you and you can leverage that if needed. We first want to resolve problems with facilities and providers themselves but if professionals or facilities have acted against

the law we can file a complaint with the oversight body and they will investigate the complaint.

- Timothy shared that he has had doctors express appreciation for learning more when Timothy brings research to them about his disease.
- Being selective about who we share private information about our disability when it can work against us is a skill we have to adopt and use and always manage. From a psychological perspective we also must be aware if we are hiding information due to shame.
- Timothy encourages participants to explore increasing their communication skills because it will help with navigating the healthcare system. He also encouraged a healthy level of entitlement in the sense that we are entitled to respect, consideration, and to be taken seriously.

### **Healthcare obstacles shared by participants**

- Specialists being out of network
- Long COVID clinics not accepting ME/CFS patients
- Primary care not being more informed
- Not enough informed providers
- Doctors unwilling to work with other specialists
- Doctors unwilling to learn
- Being dismissed or labeled as “psych”
- Difficulty advocating for needs with illness and brain fog
- Insurance denials
- Incredibly long waitlists

### **Ways forward**

- Finding a collaborative doctor
- Appeal and appeal again!
  - A few times, I talk to my insurance company and find someone who can give me specifics of my denial, then I go back to my doctor to appeal with that information in mind. I’ve had to call constantly to make sure they stay on top of things, but it worked. For things like physical therapy, I haven’t had any luck and just go less often and do private pay, which isn’t that much more than what my copay was.

- Ask for peer-to-peer with the insurance company. They will chat with your physician who will explain the medical necessity.
- As of Oct 1st, 2022, the international medical community has an officially recognized code for ME/CFS. The ICD-10-CM Code for ME/CFS is "G93.32." ICD stands for International Classification of Disease. A doctor/other medical professional can claim "lack of knowledge", but they simply need to enter this code into the database to access information describing the physical nature of this condition. (pasting this from a Facebook chat)
- A participant who had ME/CFS for many years and contracted COVID was able to be accepted as a patient at a Long COVID Clinic because she reported having been infected with COVID-19.
- A participant shared that she finds it helpful to focus on discussing symptoms with her providers rather than the name of her illness (ME/CFS).
- A participant shared that she uses BHC printouts that help explain her level of function. It helps communicate with her provider, especially when she is too tired to do a lot of explaining.
  - [Good Day/Bad Day](#) worksheet
  - [Health Assessment](#) worksheet

### Screen reader instructions and tips

- Open your device's Settings app. Tap Accessibility, then tap Select to Speak. Tap Settings. At the top, turn on Read in background.
- Natural Reader is a good app. It does cost a little a month but it's really helpful for me. It sounds like a real person instead of a robot and it can read just about anything and it sounds more natural than most free text to speech platforms.
- On a MacBook
  - MacOS it's called Spoken Content under the Accessibility Menu
  - To read text; highlight the text, press option Escape. (in the settings, click on accessibility, Spoken text, choose narrator)
- Highlight text and right click and select Speech in Safari.
- In windows the text to speech is called Narrator. <https://support.microsoft.com/en-us/windows/chapter-1-introducing-narrator-7fe8fd72-541f-4536-7658-bfc37ddaf9c6>

### Resources to share with medical providers

- Mayo Clinic Review for Clinicians: [https://www.mayoclinicproceedings.org/article/S0025-6196\(23\)00402-0/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext)[https://www.mayoclinicproceedings.org/article/S0025-6196\(23\)00402-0/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext)
- Resources for PTs and OTs: <https://batemanhornecenter.org/providers/mecfs/diagnosing-managing/rehab-professionals/>
- Mast cell related interactions: <https://tmsforacure.org/wp-content/uploads/2021-TMS-ER-Protocol.pdf>
- Long COVID & Post-Viral Syndromes ECHO repository: <https://batemanhornecenter.org/providers/long-covid/project-echo/#long-covid-post-viral>

### Medical Provider Directories

We cannot endorse any one provider or institution but know of other organizations who have provider directories. The extent, accuracy, and approach to care has not been validated by BHC, but perhaps these resources will prove helpful:

- Solve has many of the following links within this one document: <https://solvecfs.org/wp-content/uploads/2022/05/Finding-a-Doctor.pdf>
  - <https://ammes.org/physician-and-clinic-database/>
  - <https://www.meaction.net/resources/find-your-doctor/>
  - <https://solvecfs.org/me-cfs-long-covid/patient-and-caregiver-resources/>
  - <http://www.cfstreatmentguide.com/doctors-and-clinics.html>
  - <https://forums.phoenixrising.me/forums/me-cfs-doctors.32/>
  - <https://www.healthrising.org/forums/>
  - [https://docs.google.com/spreadsheets/d/1qRz6jcMX2Yx7\\_pmJqdBOFXgVJE\\_CgZ\\_SIIYNshW3XJM/edit#gid=718047883](https://docs.google.com/spreadsheets/d/1qRz6jcMX2Yx7_pmJqdBOFXgVJE_CgZ_SIIYNshW3XJM/edit#gid=718047883)

### Medication resources

- GoodRx.com is an online price checking resource
- Compounding pharmacy:
  - <https://www.belmarpharmasolutions.com/>, <https://www.cfspharmacy.pharmacy/human-medicine/low-dose-naltrexone>

### Canary Corps

A new upstart peer-led program from #MEAction that looks promising called Canary Corps to connect people with services and support related to ME, LC, and other infection-associated illnesses. <https://www.meaction.net/canary-corps/>

- Alison Sbrana's presentation last week at the Long COVID and Fatiguing Illness Recovery Program webinar, it's absolutely worth the spoons.
  - Recording: <https://www.youtube.com/watch?v=p2TOlKUnvsA>
  - Complete resource page from presentation: [file:///C:/Users/Owner/Downloads/3.14%20links%20\(1\).pdf](file:///C:/Users/Owner/Downloads/3.14%20links%20(1).pdf)
  - Specific links from presentation
    - Find your CIL <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>
    - Guidance on "Long COVID" as a Disability Under the ADA, Section 504, and Section 1557 <https://www.hhs.gov/civil-rights/for-providers/civil-rightscovid19/guidance-long-covid-disability/index.html>
    - Find Local Help <https://localhelp.healthcare.gov/#/intro>
    - Aging and Disability Resource Center <https://eldercare.acl.gov/Public/Index.aspx>
    - How to Have a Great, Disabled Life <https://howtogeton.wordpress.com/>
    - State Vocational Rehabilitation Agencies <https://rsa.ed.gov/about/states>
    - Accommodations guide <https://askjan.org/index.cfm>
    - Long COVID Accommodations <https://askjan.org/disabilities/Long-COVID.cfm>
    - About Myalgic Encephalomyelitis/Chronic Fatigue Syndrome <https://askjan.org/disabilities/Myalgic-Encephalomyelitis-ChronicFatigue-Syndrome.cfm>
    - Disability Benefits 101 <https://www.db101.org/>
    - Compounding, LDN Pharmacy <https://www.cfspharmacy.pharmacy/human-medicine/low-dosenaltrexone>
    - Compounding, LDN Pharmacy <https://www.belmarpharmasolutions.com/>

- How ACL's Disability and Aging Networks Can Help People with Long COVID [https://acl.gov/sites/default/files/COVID19/ACL\\_LongCOVID.pdf](https://acl.gov/sites/default/files/COVID19/ACL_LongCOVID.pdf)
- The Long COVID Survival Guide' to finding care and community <https://www.npr.org/2022/11/18/1137661071/the-long-covidsurvival-guide-to-finding-care-and-community>
- Community Support for Long COVID <https://www.wearebodypolitic.com/covid-19>

### General Resources

- Massachusetts ME/CFS and FM has a lot of great resources to help with navigation and patient support:
  - <https://www.massmecfs.org/services>
  - <https://www.massmecfs.org/provider-recommendation-form>
- The Sick Times
- [ME/CFS Crash Survival Guide](#) (This guide is not only helpful for patients, but also in helping caregivers and providers understand what you are experiencing.)
- [“Chronic Illness: What I Want You to Know”](#) communication card
- [BHC Patient Resources](#)

### Crisis Resources

- Dial 988
  - [What Happens When You Call 988?](#) (Article)
- Dial 911
- [Crisis Text Line](#)
- [Crisis resource page](#) (BHC)

### Support Groups (alphabetical order)

- BHC Support Group 2<sup>nd</sup> and 3<sup>rd</sup> Tuesday at 1 pm
  - <https://batemanhornecenter.org/events/>
- Black COVID-19 Survivors
  - <https://www.facebook.com/groups/bcsalliance/>
- CFS/ME Friends
  - <https://www.facebook.com/groups/CFSMEFRIENDS>

- Health Stories Collaborative Creative Meetups
  - <https://www.healthstorycollaborative.org/creativemeetups>
- International ME Support Chat
  - 11am-1pm EST/ 5 -7pm GMT / 3-5am Melbourne time & 9-11pm EST/ 3-5am GMT/ 2-4pm Melbourne time
  - <https://us06web.zoom.us/j/84362703704?pwd=bfKmegaCLNhS6KwOUve7fkcsQjs7sB.1>
- Long Hauler Advocacy Project
  - <https://www.longhauler-advocacy.org/support-us>
- Long COVID Families
  - <https://www.facebook.com/groups/4345929175466216>
- Massachusetts ME and FM Association Small Group Chats
  - <https://www.massmecfs.org/>
- #MEAction Living w/ME Support Group
  - <https://www.facebook.com/groups/211058135999671>
- ME/CFS Social Group
  - <https://www.facebook.com/groups/1202428297198122>
- ME/CFS phone support group
  - Occurs on Saturday nights at 8pm, EST.
  - Call: 609-746-1155. Punch in: 915110#. Group is open to all.
- Seattle Support Group
  - <https://www.facebook.com/groups/seattle.cfs.me.support>
- State Specific Long Hauler Facebook Groups
  - <https://docs.google.com/spreadsheets/d/1vMNCrONg1oTy5QPzajNUJffu0gk4eBR4o585NosVgsk/edit#gid=0>
- Surviving with ME
  - <https://www.facebook.com/groups/695317212152964>
- The Mighty Group Directory
  - <https://themighty.com/groupdirectory/>

## Caregiver Support

- [Caregiver Wisdom](#) is an online venture to support chronic illness caregivers. [Current free offerings](#) include: a [monthly support group](#), a [free online community](#) that's off of social media, and [a blog](#) with helpful posts.

- A support group for partner caregivers (please note all caregivers are welcome) takes place the first Sunday of each month at **12 p.m. PT / 3 p.m. ET**. We focus on monthly topics and have small breakout rooms for closer community connection. To be added to the email list, contact Kim at [kim.mecfs@gmail.com](mailto:kim.mecfs@gmail.com).
- #MEAction's support group for all family caregivers takes place the third Saturday of each month at 12:30 p.m. PT / 3:30 p.m. ET. To be added to the email list, contact Denise at [caregiver@meaction.net](mailto:caregiver@meaction.net).
- If you are on Facebook, [#MEAction has a Facebook group for caregivers](#)
- If you are on Discord, Nia has started a [channel for ME/Long COVID caregivers](#).