

## **Support Group: Managing Physical Symptoms: Cognitive issues, Sleep Disturbance, Chronic Pain, Fatigue and Disability**

*August 12, 2025*

### **Announcements**

- Sign-up for BHC email to receive the recap:
  - <https://bit.ly/3rnvhjq>
- Support BHC's One Guide. One Goal \$5 campaign:
  - [https://givebutter.com/OneGuide\\_OneGoal](https://givebutter.com/OneGuide_OneGoal)

*The following resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance or endorsement.*

Timothy Weymann, LCSW started the conversation by introducing the questions and opening the floor for participants to share their collective wisdom as the group explores the topic.

### **Discussion Questions**

1. Which symptom do you struggle with the most and why?
2. What symptoms have you gotten better at managing and how so?
3. What lifestyle adjustments have you made to accommodate your symptoms?
4. What helps you to know and remember how to respect your disability limits?

### **Timothy's Shared Wisdom**

- Imposter Syndrome can be a common experience, on a broader scale what it alludes to is internalized ableism. Ableism is our prejudicial beliefs people have about chronic illness and disability. If we are not intentional, we can get sucked up into our own psyche and feel these feelings. It is important to learn to mentally detach from the majority and define ourselves within.
- We should check in with ourselves to see if we are attuning with ourselves or with external standards. Self-connection is important when listening, respecting, and accepting ourselves.

- Being ill isn't just a biological experience but also an interpersonal, political, and spiritual one. It is important for us to validate for ourselves how much these illnesses can change things and affect other areas of our lives.
- Acceptance is an important skill in life and reframing our minds to achieving self-acceptance instead of thinking of it as giving up can help us move forward.
- We can become more hopeless the narrower and more fixated our hope is. By experimenting with broader hope and using a split brain where we hope for recovery and take action but also focus on hope for if those things don't come to pass.
- An important thing to keep in mind is that hurt frequently isn't born of malevolence but ignorance.
- Grief is an important part of acknowledging what is lost. But at times when people say grief they are focusing on ruminating or going over what was lost, but a big part of grief many miss is acceptance and reinvestment.
- Chronic illness can cause us to be very creative in how we meet our needs through accepting and adapting.

### **Verbal Comments**

- Participant described shared they experienced a severe episode of imposter syndrome, feeling guilt, shame, and self-doubt on days they feel somewhat better and worrying others might think they're faking their illness and revoke their disability insurance. They spiraled into irrational fears but found comfort by watching YouTube videos on chronic illness and imposter syndrome. They expressed frustration at being too hard on themselves and wishing they could stop this self-criticism.
- Participant who has chronic pain, fatigue, ADHD, and autism, is learning to respect their limits after a late-in-life neurodivergence diagnosis. With guidance from their physical therapist, they're practicing recognizing burnout signs earlier and taking breaks, though they still struggle to balance activity and self-care. They shared an example of leaving a hot, crowded event early, then finding joy and nervous system regulation by interacting with a dog in a nearby park. They aim to prevent meltdowns and days of PEM.
- Participant shared how valuable it has been to connect with others in the group who truly understand the experience of illness, mentioning a supportive

friendship they formed with someone in California. They reflected on the loss of identity and productivity after leaving demanding careers, which resonates with others in the group. They also wanted to share medical information: their neurologist is testing them for myasthenia gravis (an autoimmune disease sometimes linked to COVID-19). They noted studies suggesting COVID-19 can trigger MG, with winter infections associated with both higher risk and milder symptoms. They offered this information so others might consider it as a possible avenue to explore.

- Participant expressed worst symptom as frustration that their doctor dismisses their symptoms, leaving them feeling unsupported. But as of lately POTS symptoms being the worst, combined with wildfire smoke and heat making things worse. They shared deep gratitude for help. To cope, they rely heavily on coherent breathing, which stabilizes their heart rate. They also manage symptoms with careful lifestyle adjustments, journaling, calendar tracking, and health technology (Fitbit and Vivo Active 5) to monitor patterns and energy levels.
- Participant shared that their worst symptom is pain. They wanted to share with the group that they feel that their symptom can win despite the measures they take to prevent it from winning. They have found it helpful to patiently endure the symptom and hold up their white flag and learning not to feel bad about it.
- Participant shared that the symptom they struggle with the most is sleep. They are trying things like naturally waking up and cutting out coffee in hopes for this symptom to get better.
- Participant shared that the symptom they struggle with the most is post-exertional malaise (PEM). They have felt very frustrated with many relapses but are finally finding that since starting their KETO diet some of their symptoms have lessened.
- Participant shared their journey with Long COVID and hoping to return to baseline but that has not happened for them yet. They have scaled back activities so they aren't seeing their friends and family as much and they are working through the feelings of what they need to accept in their life as far as their abilities.
- Participant shared that they currently suffer from three illnesses and don't enjoy getting older. They said that they have made lifestyle changes such as

acupuncture, moving into a CCRC retirement community. They described the major adjustment as hard, but once they became well-adjusted they found classes and people that make it easier. They said that while it is tempting to do everything, they think carefully about which activities might overdo it.

- Participant shared that they have had ME/CFS for 11 years and have always had a lot of difficulty with symptoms and would find themselves in denial when in PEM. They shared that they made the lifestyle change of getting a walker and hated it at first but now find it helpful when they begin to crash or need to rest in public.
- Participant shared that their worst symptom is crashing very easily, in an effort to avoid crashing they have had to cut many things out which makes their world feel very small. They struggle with ways to get past the feeling of disappointment from not getting to live the life they thought they would.

### Chat Comments

- “For anyone who wants to connect between calls, we made a group: <https://www.facebook.com/groups/CFSMEFRIENDS>”
- “4. Experience and my husband who reminds me and notices the signs of my fatigue”
- “What helps me TREMENDOUSLY is pacing. With this tool, not living beyond my limits, accepting my boundaries and then making time to recuperate, regroup and catch my breath after an event, I can do more.”
- “1. Dysautonomia, fatigue, PEM”
- “1. Migraines - chronic, prolonged and intractable.”
- “Pacing is everything.”
- “1. Brain fog. Makes me feel like I'm not even myself.”
- “Ongoing breathlessness with no explanation (medically)”
  - “My breathlessness turned out to be related to stomach issues— GERD and dyspepsia. If you haven’t talked to a GI doc it might be worth it!”
  - “Do you have POTS? Or have you been tested for co-occurring illnesses like Tic born disorders. “
  - “My SOB is POTS related.”

- “My doc put me on Elavil for IBS, and increased it when I was having more upper GI issues; I think it helps”
- “3. Pacing, resting and not over committing myself.”
- “This support group hearing people with similar experiences helps me remember how to respect my disability limits.”
- “1. My biggest struggle right now is trying to find a provider who understands the disease and can give me a diagnosis (or prove to me it's something else) while also trying to learn about it, and totally reorient my life and energy output to respond to it, including interactions with my young kids, all at once. It's incredibly overwhelming.”
- “I have a love/hate relationship with pacing. A necessary evil.”
- “NEVER book things back to back days, nap and only stay as long as makes sense that day.”
- “I also have adrenal fatigue and take Cortef (cortisol). I need to have doc manage it better, so I increase under increased stress. Balancing symptoms and meds is a roller coaster.”
- “It is a mind shift to go from getting your identity from what you can DO to who you ARE. But actually that is a truth that we all need to know, we are worthy must because we exist. It might be a lesson we are supposed to learn from this experience.”
- “In a world that tells us we should always be doing more, sitting still can be an act of rebellion, the ultimate rejection of a culture that tells us our value is tied to our productivity. Christopher Rivas, *'I Think the Clock Is Broken'*”
- “2. My GI symptoms improved - I eliminated many foods and have small meals and never eat late in the day. Sometimes I'll skip meals in the evening which helps when I am severely fatigued.”
- “I switched my PCP from an M.D. to a D.O. He's much better at understanding what I contend with.”
- “Try to get to see (online) Dr Arseneau in Vancouver! Your doctor might be able to connect you. He specializes in me/CFS—does workshops, etc”
- “POTS is one of the few things that you can check for yourself by monitoring you heart rate and blood pressure going from laying down to standing. A change of 30bpm or more is POTS.”
- “Love the Visible tracker”

- <https://www.makevisible.com/>
- “Coherent breathing. Also known as resonant breathing or heart-focused breathing. The HeartMath Inner Balance device and app are incredible for helping to track and improve HRV.”
- “I drink a glass of water with electrolytes in bed first thing in the morning. Then I lie back down and don’t get up for 10 minutes. (I also have POTS)”
- “I’m doing lots of work on deep breathing and meditation and work on vagus nerve.”
- “I’ve found music therapy to help me pace, as well as calm down and relax a lot.”
  - <https://www.psychiatry.org/News-room/APA-Blogs/Power-of-Music-in-Mental-Well-Being>
- “I also have POTS and take daily Klarlyte electrolytes caps and has helped a lot.”
- “It’s definitely a matter of trial and error to see what works on an individual level since we are all different in our own way.”
- “Eating a very low carb diet helps me tremendously.”
- “Where can we find resources for disability in case we can't work or can only work a little (in the United States)?”
  - <https://howtogeton.wordpress.com/>
- “Somatic tracking and yoga nidra are good meditations that help me.”
- “In Oregon, we have aging and disability support with the county. I suggest checking county resources in your area.”
- “Sunshine is sometimes the dappled light through the leaves I have been trying to find hope in small things.”
- “The Decode ME/CFS genome project results are in a preprint and you can join Science4me to access the discussion.”
- “1. Fatigue. It makes me feel like I'm unable to do much of what I used to do. 2. PEM. Learning to regulate my spoons usage. I refuse to use my spoons for anything negative or things I can't control. 3. Changed my pace of life to slow mode. Learning to pace myself has been huge. 4. Using my spoons wisely. I can anticipate PEM episodes better now when I choose to use all of my spoons on a task.”
- “I liked the concept of a dual consciousness, doing whatever I can to feel better while at the same time accepting that this is my life right now. Acceptance brings me peace.”

- “I stumbled upon the idea that happiness comes from within and doesn’t rely on external forces including how our body functions. I continue to look for quotes, books, talks, etc. that give examples of that. I strive to remind myself of this.”
- “Who knows the name of the online place for meditation? where you can come and meditate online with a group of people?”
  - “I love the YouTube channel Lavendaire for meditations and positive affirmations... it's not a group meditation though, just a video, but it's another resource”
  - “Insight timer is wonderful and free! I couldn’t get by without it.”
  - “Live online groups by affiliation <https://eastbaymeditation.org/sanghas/>”
  - “<https://studiobe.community/> There on a summer sabbatical but starting up again in sept. It’s awesome. All of Pat’s classes are amazing and a meditation with breathing exercises. Even if you go to the restorative or yin classes, you can use the whole hour as a mediation. And not do any of the movements...at least that’s what I do.”
  - “Center for mindful self compassion circles of practice, 3 live sessions each day.”
  - “Free every Tuesday: <https://www.breathworks-mindfulness.org.uk/live-tuesday-meditations-with-vidyamala>”
  - “Free yoga nidra/body scan 2nd Friday of the month: <https://daringtoforest.com/>”
- “Are there any ME peer mentoring programs?”
  - “The CFS self-help site isn’t a formal mentoring program but checks some of those boxes (online courses and message boards with supportive folks).”
  - <https://cfselfhelp.org/>
- “Compounded Sermorelin, a peptide precursor to growth hormone, has helped my fatigue a lot. I still have fatigue but it’s not as bad.”
- “Shower chair has helped me a lot for POTS and toilet stool for IBS.”
- “The documentary Crip Camp help me get an electric tricycle/start getting comfortable with asking for accommodations. My scooter is from Amazon called Topmate.”
- “1. Which symptom do you struggle with the most and why? Not being able to be present in my mind and my body. It affects symptoms, being able to move,

interact, think etc. 2, 3. What symptoms have you gotten better at managing and how so? Pacing. It's difficult to do, but it seems to help limit (delay?) some symptoms like Orthostatic Intolerance, e.g. stopping and having to lay down every 45 mins or 1 hour. 4. What helps you to know and remember how to respect your disability limits? Know what my limits were when I was much worse a few years ago, reflecting on that and not pushing significantly beyond. I've tried using timers and alarms to rest and take a timeout also."

- "I find irritability and mood symptoms to be some of the worst symptoms that come and go. They makes me and everyone around me miserable. It's a kind of neuro-pain but not a headache. It fits with the brain inflammation they are finding in ME/CFS studies but it's very hard for other people to understand. I find pacing to help the most. I think the effect of PEM on the brain and emotions is underappreciated since medicine has traditionally separated personality and psychological symptoms from physical symptoms and most people assume things like irritability are just a personality problem that you can easily control but at least in this case it's a neuro-pain that's as bad as any physical pain."
- "We have to listen to our body, even when we don't like what its saying. It's so not easy but helps us from getting worse and totally crashing."
- "I don't think we will get to my raised hand, so I will put it here: 1. If you think you have POTS keep pursuing a diagnosis. A cardiologist's office did a stand test wrong on me, and it came back no issue. My functional doctor used Bateman Horne's materials to do a nase lean which CLEARLY showed OI and POTS. Now I am on medicine that is helping. Keep pursuing help. 2. I paced with Garmin and kept getting worse. Visible has shown me that I have a smaller energy budget than I thought based on Garmin. I was running Garmin down to 5-10 each day and it turns out I needed it to get no lower than 30ish to be stable."

### **Tiny Triumphs**

- "I was able to put up my outside RV window shades for the first time in a few years."
- "Attended a wedding reception last Fri for 2 hours!!!"
- "Finding this support group <3"
- "Woke up at the perfect time of night to see the full moon from my window."

- “Sprouted some flower seeds.”
- “Took a nap instead of pushing myself too far!”
- “Recognized I was heading towards a crash and decided last night to take today off of work.”
- “Set up a physical PEM tracking journal and it’s helpful.”
- “I completed watching a webinar and got a 1 PDU certificate for it :)”
- “Taking a shower and washing my hair! A huge undertaking with POTS and ME/Long Covid.”
- “Got to sit outside in the sun for a bit.”
- “Took all my medication correctly.”
- “Found simple PT exercise that actually helps shoulder pain!”

## Resources

- [ME/CFS Guidebook](#)
- [Pacing Education Modules](#)
- **Crisis Resources**
  - Dial 988
    - [What Happens When You Call 988?](#) (Article)
  - Dial 911
  - [Crisis Text Line](#)
  - [Crisis resource page](#) (BHC)

## Potential Financial Assistance Resources

- [Healthwell Foundation](#)
- [Patient Access Network Foundation](#)
- [Needy Meds](#)
- [My Good Days](#)

## Support Groups (alphabetical order)

### Lived-Experience Support Groups

- Action for ME (online youth support based in UK)
  - <https://www.actionforme.org.uk/18-and-under/support-for-under-18/join-our-young-peoples-community/>

- BHC Support Group 2<sup>nd</sup> and 3<sup>rd</sup> Tuesday at 1 pm MST
  - <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>
- Invisible Youth Support Group
  - <https://www.facebook.com/groups/invisiblyouthgroup>
- 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>
- #MEAction Long COVID Group
  - <https://www.facebook.com/groups/205703087068863>
- #MEAction Seniors Connect
  - [https://www.facebook.com/groups/391269901334695/?ref=pages\\_profile\\_groups\\_tab&source\\_id=1408335399448862](https://www.facebook.com/groups/391269901334695/?ref=pages_profile_groups_tab&source_id=1408335399448862)
- #MEAction Pillow Crafters (Group Crafting Sessions)
  - <https://www.meaction.net/pillow-crafters/>
- #MEAction Additional Groups
  - <https://www.meaction.net/groups/>
- 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.
- 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/>
- Utah COVID-19 Long Haulers
  - <https://www.facebook.com/groups/2619858348232191>
- The Yarrow Collective's Alternative to Suicide group is a weekly Zoom meeting. It's a free resource for folks who are struggling that is nonclinical peer support. They also have chronic illness and disability support groups.
  - <https://www.yarrowcollective.org/>

## 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**. Focuses on monthly topics and has small breakout rooms for close 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](#).