Support Group: Tapping Into the Collective Wisdom of the Group

May 13, 2025

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
    - https://batemanhornecenter.org/outreach/newsletter/

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

Angela Linford, BHC community engagement lead, began the session with a presentation of the Reflections of ME/CFS and Long COVID digital board in honor of awareness month. Members of the community submitted photos, writings, and videos focused on their experience with ME/CFS and Long COVID. The digital board will remain open for submissions.

Following the Reflections presentation Meredith Mehner, LCSW introduced herself as a former support groups facilitator and shared that she stepped away from this role due to becoming ill with Long COVID. Meredith has experienced some improvement and is filling in for Timothy Weymann, LCSW as facilitator for this session. She explained that this session is designed to honor our experiences with chronic illness and share the wisdom gained. Meredith noticed in the submissions that our voices have become clearer and that we finally have language to describe our experiences.

The following questions guided the discussion.

1. What wisdom have you gained from dealing with invisible illness? In terms of your own body, your relationship to others, your relationship to self, to life, etc.

2. What creativity has come from this wisdom and how does it affect your paradigm of what makes a meaningful life?

Meredith's Shared Wisdom

- She shared the quote, “When marginalized people gain voice and center their own experiences things begin changing.”
- The author, Glennon Doyle, said there is not more room for self-help. There is only room for collective wisdom now.
- We rarely know what state our body is going to be in so we must embrace what is happening in the moment. There is a struggle with not having our experiences reflected back from medical providers and society that causes us to dig deep inside and show the missing compassion to ourselves.
- Often people who get these illnesses are those who were taking care of others. It can be difficult to make the shift from being the helper to one who must ask for help.
- It is important to do things that bring us joy and make us feel alive because we deserve to feel alive.
- It is important to become aware of which people can be energy draining and who gives you energy and life. If Meredith has one spoon for the day, she better use it on something that will be joyful or help her feel okay in her body.

Participant Verbal Comments

- Participant shared that the last several years of his life has been defined by learning to slow down and enjoy and not take for granted the little things.
- Participant shared that learning to manage his spoons and knowing when he must use all his energy which will result in a crash (post-exertional malaise). He can now understand what is happening to his body when he overexerts and is managing his spoons much better than ever before. He lives in his RV full time and takes six weeks traveling from Washington to Arizona (1,200 miles) to spend the winter.
    - Learned to stop spending spoons on things he couldn’t control.
    - Learned to use spoons for things he could do.
- Participant commented that each Reflections submission included wisdom, and she appreciated the people who spent the energy to share their lived experience. She has learned that individuals with ME/CFS have some of the most wisdom in the world because of what the illness has taught them. The impermanence of life is so valid that we only have right now to live it as a gift.

- Participant has learned that vulnerability is the antidote to isolation. He has a vlog and is on a mission to make our invisible illnesses visible. He initially only created informational videos about Long COVID but has since posted videos that show how the illness manifests in him. https://www.youtube.com/watch?v=MEkMXGDU4nc
- Participant shared that they have learned how to ask for and accept help from others.
- Participant has learned how amazing people with ME/CFS can be. She is a congressional representative and while on Zoom tilts her camera in a way that people don't know she is in bed. This adaptation helps to level the playing field when she is advocating in a professional environment.
- Participant shared that she stopped focusing on the people who are bad for her and instead she focuses on the people who enrich her life.
- Participant has learned to be kind to himself.
- Participant has learned that even though she is bedbound new people still come into her life who help to enrich it. She meets them through online groups.

Participant Comments from the Chat

- "I used to think that I was fighting for my life. I have learned that I am fighting for MILLIONS MSSING! It is much easier to fight for the collective when you are the WEAK ONE. 💓"
- "Question 1: I've gained more patience and compassion and become less judgmental. If what I'm going through is challenging to understand and is invisible for others to see, I try to extend that to anyone else who has invisible illnesses and conditions and believe them. I am also much more protective of my energy and who and what has access to it."
- "Question 2: I believe I am more flexible in listening to my body and needs in all moments. Meaning is in believing I am worthy of care and nurturing. I am more kind to myself five years into this illness journey and try to take each day as it comes. Groups like this have meant the world to me with so many useful strategies I implement into my daily care."
- "ME has taught me to slow down and appreciate the smaller things, taking the time to tell family I really appreciate them."

- “My YouTube channel is called Long Covid Musings & Moments, and here's my new video Invisible No More: https://www.youtube.com/watch?v=KivZOLIY91c&t=6s”
- “I was able to write a children’s book from bed that explains chronic illness to a child. I would have never done that had I not become bedridden because of this disease. It’s one thing that has brought me joy. I never knew I was creative in that way. https://hazymaybooks.com/product/twirl-with-me-mama-hardcover/”
- “ME is teaching me not to be understanding of others to my own detriment. (I grew up with teaching that I should be caring and understanding of others, but it was in disregard of my own needs and boundaries)”
- “Some Buddhists believe allowing others to help you helps the people helping to get good karma/learn compassion so letting others help you helps them.”
- “I'm reluctant to ask for help too, and did a video on this: https://www.youtube.com/watch?v=rRlMTT9AOrg&t=272s”
- “During my 3rd episode I found quilting which brings me so much joy.”
- “When I had to retire due to ME/CFS, I joined the Pillow Writers group. Now I take writing classes to distract me from the pain and frustration but that uses most of my energy.”
- “It is certainly a challenge and a moving target! Really appreciate comparison of a gas gauge without a needle. This is one resource to check out: https://cfsselfhelp.org/pacing-tutorial”
- “Make resting the norm; doing stuff is always the exception. Say no and set boundaries. Look for signs that you’re doing too much— I’ve noticed if I get more sensitive to sound or have the urge to sit down at odd times, that’s a sign I need to stop immediately.”
- “This group has helped me let go of my anger and find the words to educate my family and friends. I’m much more content now and also have more compassion.”
- “People have often mentioned Toni Bernhard's books as helpful. Alex Elle's books and Nedra Tawwab's work on boundaries and healing. Might be worth checking out!”
- “I agree sensitivities flaring to let you know you are overdoing. I get bad nausea and heart rate gets too high, know I need to rest. I get almost daily headaches and recently trying Botox for the headaches/migraines which has helped a ton! I

recently am using a pacing activity and resilience app that was developed for someone with severe ME/CFS. It also has the body battery built in after 5 days once installed on your Garmin watch. I have Vivo active 4 & Garmin Venu watch. I wear both."

- "Wisdom to be able to do the things that I can do when I can. Pacing is still difficult but getting there hopefully. Wisdom that many things aren't what they are at face value. Wisdom to appreciate peace when it is present and trying to spot it."
- "Guided meditations from purely being help me. Her one about not resisting is good."
- "You have survived everything that has happened to you so far!"
- "Yoga Nidra meditation is very helpful."
- "Finding to do lists to break things down into sections and getting support with each different part so it makes things feel more tangible."

Resources

ME/CFS and Long COVID Education Modules

ME/CFS Crash Survival Guide

Clinical Care Guide

Independent Living Resource Center (link goes to the Utah site but you can navigate to other states from the page)

Crisis Resources

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

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 2nd and 3rd 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/invisibleyouthgroup
- 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
- #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/
- 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 closer community connection. To be added to the email list, contact Kim at 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.
- 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.