

## **Support Group Recap: Effective Coping Techniques for Living with Chronic Illness**

*January 14, 2025*

### **Announcements**

- Subscribe for Zoom recaps, updates, and invitations for future events.
  - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is recruiting for clinical trials. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.

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

Timothy Weymann, LCSW introduced the topic by explaining that he wanted to start the year off with a general survey drawing from the collective wisdom of how people in this group are surviving and thriving while living with a chronic illness.

### **Discussion Questions**

- 1. What behaviors and practices do you find to be helpful in bringing you peace amidst chronic illness?**
- 2. What ways of relating and communicating with others brings more "ease" to your disease?**
- 3. What attitudes and perspectives/frameworks do you find helpful in building courage and resilience in the face of illness?**
- 4. How do you build a sense of power amidst the uncontrollable?**
- 5. What approaches to coping with illness have you learned are unhelpful for you?**

## Timothy's Shared Wisdom

- A recurrent theme for a lot of folks is the conflict of listening to our bodies and taking care of the demands we have. Many have learned the hard way about crashing after overdoing it and pushing too hard.
- In the first years of Timothy's illness, he created a 1 to 10 energy and pain meter. He went by each number and wrote down which activities he could do when he was at one of those numbers. This process brought more order and helped him to better pace. When he woke up in the morning, he would do a body scan to assess which number on his scale he was at.
- It is important to have a filter like a theoretical screen and not an open door for information we take in such as the news. That concept can also apply to relationships.
- There is an a-religious spiritual practice that is science-based and has been shown to help people with illness. It can include mindfulness, gratitude, and creating meaning and purpose.
- Boundaries in relationships become especially important if we have people in our lives with narcissistic personality structure which is defined by high entitlement, low empathy, and propensity towards exploitation. They don't deal with illness well in other people because they are rigid and self-focused.
- Research shows that when we have relationships that are high in emotional constraints where we are not free to express who we really are that our illness symptoms get worse.
- Continuity of identity can be very important, and it can be destabilizing to be identified with what we do as a job or a capability that we don't have anymore. One way to cope with that is to reclaim aspects of our identity within our limitations. For example, Timothy values education and while he had periods of time when he couldn't work, he could still learn from his bed by taking online courses or reading books. Finding activities that get to the core of your identity can help.
- When we are challenged by accepting the new reality a good approach can be to identify blocking beliefs. For example, ask yourself what you believe that is preventing you from accepting and thereby adapting. We want to identify those

and critically examine them because they can be irrational or extreme or just not helpful. An example of a blocking belief is, “My life is unbearable if I can never bike again.”

- Some of the skills that help us excel in the work world will fail us in coping with chronic illnesses. Rather than competition and pushing to produce we need to adopt a different philosophy that is more about peace and recognizing the uncontrollable submission.
- During acute pain it’s better to try distraction techniques such as a bath or music rather than mindfulness.

### Participant Verbal Comments

- Participant explained that the societal pressures we feel to be productive make it hard to learn the lesson that we need to listen to our bodies and pace.
- Participant shared that having a friend who also shares the same limitations and health challenges is helpful because she doesn’t get sick of hearing complaints but also can celebrate the wins of having a good day.
- Participant identifies the things that upset her and tries to avoid them like watching the news and future tripping.
- Participant shared that practicing acceptance and gratitude has been helpful for her. At her sickest she was grateful for a spot on the wall she could focus on in the dark. Now that she is healthier, she is grateful for her pets.
- Participant has found it helpful to prepare for crashes and flares because it lessens them. For example, she has a toolkit of foods for crash days or days she needs to leave the house.
- Participant is active in a 12-step program and has found it helpful to have a fellowship of people to call who are using spiritual principles of gratitude and service. He has found a resource by Mindful Leaders called *Meditate Together*. They offer 20-minute meditations on Zoom every hour followed by 10-minutes of reflection.
  - <https://www.mindfulleader.org/meditate-together> It’s \$5/month or \$40/year
- Participant explained that she finds comfort in memories of loved ones who have passed.

- A participant shared that she finds hope and life force in this online support group community and encouraged everyone to love themselves and to acknowledge that even though you don't know who you are any more, you will and you are worth the best of everything no matter your current state of pain or your mind.

### Participant Chat Comments

- "Following disability activists on social media and taking apart my own ableism has helped me tremendously."
- "When I get the tremor I lay down, drink lots of H2O and use a heating pad helps."
- "I have found CFSHealth.com to be a very supportive and powerful organization to guide me in my recovery. Practical everyday tools it gave me."
- "Sharing daily gratitude lists with others, listening to my favorite music help with the peace of mind for me."
- "Similar to Timothy's suggestion, my counselor helped me with something she called behavioral activation. I can't find a similar example from googling, but the way she had me do it is:
  1. Make a list of the activities I want and/or need to do
  2. Rate each 1-10 on energy needed
  3. Rate each 1-10 on how satisfying the activity isThat way you have it as a resource so you can start from your energy level and choose something that is rewarding."
- "I've found inner peace through less energy-costly hobbies (learning languages, meditation, watching documentaries) as opposed to the very energy-costly ones (running, hiking, skiing, going above and beyond at work) that I used to define myself by as a male in my 20s."
- "If I'm having a bad day, I do this: name 5 things I see; name 4 things I feel; name 3 things I hear; name 2 things I smell; name 1 thing I taste."
- "Icy hot, TENS, compression sleeves, and lidocaine patches are my best friends. Sometimes I try too hard to control my symptoms to the point I get more frustrated/tired/in pain, and I have to accept that I'm exhausted, I'm in pain, I'm not doing the things I want to do, and that's okay."

- “The Five Remembrances are a Buddhist practice that involves contemplating the impermanence of life and the inevitability of change:
  - ‘I am of the nature to grow old. There is no way to escape growing old.’
  - ‘I am of the nature to have ill-health. There is no way to escape having ill-health.’
  - ‘I am of the nature to die. There is no way to escape death.’
  - ‘All that is dear to me and everyone I love are of the nature to change. There is no way to escape being separated from them.’
  - ‘I inherit the results of my actions of body, speech, and mind. My actions are my continuation’
- “This is for people living with chronic pain and chronic illness. <https://chronicpainanonymous.org/meetings/find-a-meeting/>”

### Session Related Resources

- [Pacing and PEM video](#)
- [MEAction.net/resources/find-your-doctor/](https://MEAction.net/resources/find-your-doctor/)
- [Good Day Bad Day Questionnaire](#)
- [Pain Tools Amidst Difficult Moments support group recap](#)
- <https://howtogeton.wordpress.com/social-security-disability/>

### 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

- 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 (started by participants of BHC support groups)
  - <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/>
- 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](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](#).