Support Group: When Our Bodies, Life and/or Others Don't Cooperate - Coping When Things Don't Go the Way We Want Them To

September 15, 2026

Announcements

- BHC online event schedule
  - 1st Tues: Support Group
  - 2nd Wed: "Coffee" with a Clinician
  - 3rd Tues: Support Group
- Events Calendar: https://batemanhornecenter.org/events/
- Previous Session Recaps: https://bit.ly/3ORcT1T
- Clinical Care Guide: https://batemanhornecenter.org/clinical-care-guide/
- Support BHC's mission: https://givebutter.com/BuildingAccessNow

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

Timothy Weymann, LCSW, opened the session by discussing how people living with chronic illness cope when our bodies, life circumstances, or other people don't cooperate.

Guiding Questions

1. What's an area in which you struggle with other people, your body of your life not "cooperating" with what you want?
2. What helps you cope with the uncontrollable?
3. What's a way of dealing with things not going the way you want that you have found to be unhelpful?
4. How do you access a sense of freedom amidst disappointment?
5. What do you wish you could learn to handle or do in facing a lack of cooperation from your body, life, and other people?

Timothy's Shared Wisdom

- Compassion, at its heart, is being with what is, without judgment or resistance. When the body isn't cooperating in a given moment, the practice is to not resist that reality and to refrain from judging it, or ourselves within the experience.

- Given our limits, where we place our energy and attention matters enormously. Being intentional about our focus is itself an important coping skill.
- When others meet our pain with dismissive explanations ("that's just aging," "but I thought you were doing better"), it is often because the reality of our suffering is too much for them, so they self-soothe with an explanation. If we aren't mindful of that, we internalize it and feel badly about ourselves, rather than recognizing it as the other person's limitation of empathy, communication, or capacity to sit with a hard truth. The inquiry is, "Is this really about me and my communication or about my health/illness, or is this about the other person?" And we can be discerning about whom we choose to invest energy in, in regards to our explanations; explaining ourselves to people who have no interest in understanding is a lost cause and a waste of our precious energy.
- There is an important difference between self-pity and self-compassion. Likewise, blame, whether aimed inward at ourselves or outward at others, is often a sign that we are still struggling to accept that we don't control something, and blame can be an unhelpful resistant to facing the reality of that vulnerability.
- We have a relationship to the things we can't control, just as we have a relationship to people. It helps to notice our pattern: do we go into denial, do we blow up, do we pile on "shoulds"? Just as endless "you should" expressions would create tension in a relationship, telling our circumstances how they ought to be aggravates our own distress and fuels our denial. At the same time, we can honor the mind's positive intention (it is trying to figure things out and pursue what we want) and treat aggravated flare-ups as especially important invitations to be self-gentle, self-kind, and self-patient.
- A grounding inquiry when we're overwhelmed by a complex or difficult situation: is it my job to solve this, or is it my job to be present with it to the degree that I respect my limits? Being present, within our limits, can be its own solution to situations.
- Shame is a very normal experience to wade through in response to illness. It is a felt sense in the body tied to rejection, or the anticipation of rejection, and it is usually attached to a negative belief we hold about ourselves. A useful practice is to name that belief and then honestly evaluate how true it really is, and to get clear with ourselves how we really even know the truth.
- It helps to hold a "dual consciousness." Acceptance is not resignation; it is recognizing our boundary of power and working within it, a boundary that keeps shifting because chronic illness is dynamic. One half of the dual consciousness is that recognition and acceptance. The other half is continuing to pursue whatever we can to improve our

situation, while holding the mindset, "and if I don't get better, this is how I will still live a life that has meaning and moments of joy for me."

- Just as we have to work through our own denial, we have to navigate other people's denial without personalizing it. When someone can't take in what we're living with, that reflects their capacity, not our worth. On some level we can even feel glad for them that they don't yet have to understand this from their own personal experience.
- Resilient people focus on what they can control; those who are more depressed and anxious fixate on what they cannot control, reinforcing their own sense of disempowerment. Even when a circumstance is genuinely outside our control, we can still access a sense of power by choosing how we relate and respond to it, whether we tighten, resist, deny, and force, or move toward acceptance.
- Embrace and respect your limits, and stay patient with yourself, because the illness is dynamic. What we could do one week or one month we may not be able to do the next. Releasing a static mindset of illness means that when PEM or a setback returns, we meet it with natural disappointment rather than shock and despair.

Verbal Comments

- Participant shared that, with quite severe ME/CFS and eight months bed-bound, they are only now learning the real subtleties of pacing and feel the painful contradiction of a disease where five minutes of something they love can cost three days of recovery. They wonder whether they must sacrifice small joys like Wordle, Spelling Bee, Duolingo, and even support groups when they feel themselves heating up.
- Participant shared that their answer to what is unhelpful is mindless, doom, or any other kind of scrolling. With PEM you often can't tell what will trigger it until it has already arrived, and the phone offers itself as a way to calm the nervous system while keeping us in total passivity, a struggle they noted is not unique to spoonies, pointing out that even schools are now banning phones from classrooms. They try to be mindful when they catch themselves but feel up against an entire technological world.
- Participant shared that one of the hardest things is family. They and their husband moved from the Bay Area to upstate New York a year ago specifically because family promised to help, and that help never materialized. Leaving a community of tremendous support for a place where they have none has been emotionally devastating and isolating, made harder because illness makes it so difficult to go out and build new friendships. They spoke of feeling that their own late parents, who were deeply caring, would be heartbroken to see family not helping family.
- Participant shared how frustrating it is to try to make people understand, especially with cognitive issues that make communication itself hard. They described the

exhaustion of every day being a guinea-pig day of testing and adjusting, and the disheartening pull toward giving up on correcting people or asking for what they need.

- Participant shared, as a former journalist, that not being able to communicate what they're going through has been its own struggle, and that what has been most unhelpful is spending too much time wallowing. Having lived with depression before becoming ill, they know how easily they can fall into a pit of "this is unfair," and that big emotions can directly trigger PEM. They now rely on slow breathing to bring down anger and sadness, and on a phrase a therapist friend shared: "This is a moment of suffering. Suffering is normal. May I be gentle with myself?" What they value especially is the reminder that it is a moment.
- Participant shared that they are currently trialing time without their Visible band to re-learn how to tune into their body's own signals. They named the gaslighting we do to ourselves: the surge of hope on a good day ("maybe I'm not as sick as I thought") followed by the crash and the swing back to "maybe I shouldn't have tried to live my life." They also acknowledged the paradox that being mindful is itself exhausting when you're too fatigued to think straight.
- Participant shared they are struggling to picture what work will look like going forward, whether continuing is simply hurting their body, and how to hold big emotions for clients who look to them when they are having such a hard time with their own.
- Participant shared that, mostly bed-bound and homebound except for medical appointments, their struggles include the loss of an in-person social life and environmental factors entirely outside their control: wildfire smoke, months of building construction. What helps them cope is their Indigenous spiritual and cultural traditions and daily mindfulness practices (singing, journaling, meditation, and breathwork during bed rest), along with venting to their journal or their daughter, and this support group. Above all, they keep reminding themselves that none of this is their fault and that they are doing the best they can in any moment.
- Participant shared, as someone new to the group, that after thirteen years of manageable chronic fatigue an infection in February made everything markedly worse, now needing at least five hours lying down each day, with far less energy and far less going out. After a rough couple of weeks, they've reverted to self-blame, replaying the past and wondering if they somehow caused this, while trying hard to stay in the present through meditation. They are unsure whether they are in a mourning process or still working toward acceptance.

- Participant shared that starting LDN and LDA this year gave them more energy than they've had in three years, going from showering only a few times a year to roughly every ten days. What they didn't expect is that more energy doesn't solve the body's non-cooperation; it just changes what the non-cooperation looks like. Still unable to gauge the true cost of an activity, they overspend and land back in bed and recently couldn't manage a shower before a doctor's appointment, which spiraled into self-blame and the feeling of losing their abilities all over again. Their old strategies for a lower-capacity body no longer fit, and they feel lost and discouraged.
- Participant shared a powerful account of coping with the uncontrollable during three brutal weeks. They got through it with only a minor three-day crash by repeatedly practicing acceptance of their limits, refusing to try to rescue everyone, grounding in "what's happening now," setting firm boundaries with family, journaling heavily, and studying and applying self-compassion, checking in with themselves every few minutes to ask not how they should feel but how they actually feel, and honoring it.
- Participant shared that they use a wheelchair when out in their neighborhood, a striking change for a formerly hyper-active person. Because they often can't speak more than a sentence or two, they carry a friendly note that answers the common questions people have, warmly explaining why they're in a wheelchair and gasping for air, so they don't have to spend the energy explaining themselves at every barbecue or gathering. They've found it enormously helpful.
- Participant shared that they feel ashamed and embarrassed to have Long COVID, a jarring shift for someone who was high functioning in their profession and family before becoming ill nearly two years ago. They realized last week that they will have to move through a grieving process for their former life and voiced a common fear: that going through acceptance might mean leaning into the illness or resigning themselves to never getting better. Simply being part of these groups feels like a sign that they're working toward that.
- Participant shared that they and their husband have both had long COVID for three years, and that their own experience helping a young relative with ME/CFS move house in 2023, seeing people "in the bloom of youth" who were bed-bound and housebound, taught them how genuinely hard it is to grasp this illness from the outside. Even trying hard, in good faith, it didn't fully make sense until they lived it themselves. Remembering that has helped them let go when others don't get it: they explain as much as their energy allows and then release it.
- Participant shared that after six-plus years of illness they used to think they were compartmentalizing their feelings when really, they were shoving them down, and

that a big explosion of emotion reliably brings PEM. They've since learned to trust themselves enough to let feelings come, giving themselves permission to have a whole sad day when a Saturday event fell through. Bed-bound since December, apart from two intense surgeries this summer, and with an ADHD brain that loves novelty, they cope by seeking out small new joys: currently, silly cat stickers for the journal where they log everything.

- Participant shared that after twelve years of illness and years of denial, fighting the illness while pushing hard to work and then resting hard, sometimes for twenty-four hours, just to get back to work, the group has helped them work toward accepting their illness and their relationship with a body they were, at first, very angry at. They noticed a hard paradox: as acceptance deepened and they began pacing and resting more formally, they became internally restless, fighting the very rest they need, never quite putting their head all the way down, and sliding from crash to crash. They are still learning to truly let their body rest.

Participant Comments from the Chat

- "I struggle with how dynamic ME/CFS and hEDS are and that it's difficult to gauge how my body will feel and react day to day, or even hour to hour. Pacing is a forever moving target!"
- "Especially making sure we don't miss out on any research or possible "cure"… we could scroll 24/7 and it's not helpful."
- "I take notes on every single PEM: what symptoms I was noticing or ignoring, what activities and for how long. It's imperfect, but I gotta learn from my own experiences."
- "Unhelpful is also people who ask to help and, when told how they can, don't follow through. I was very mad, then sad, about that last week. Now seeing that it's a reflection on them, not me."
- "It is heartbreaking when you and your illness don't fit into their world view, so they change it to what is acceptable to them, and it hurts you."
- "People do not know how to compassionately talk to those of us with long-term health conditions! You're right, Timothy, it's their limitation, their issue. Still hurts though."
- "That's the one that gets me: 'I thought you were doing better!' They mean well, but ughhhh."
- "When does feeling our grief turn into wallowing? It's a fine line, isn't it?"

- "I get upset and allow myself up to an hour of wallowing, and then I have to distract myself with something, anything, even if it's just imagining I'm a fish or something silly like that."
- "You can still grieve and participate in other aspects of your life, even joy."
- "Self-talk is SO helpful. Be honest, open, and fair with yourself."
- "Checking out instead of checking in. Living in my head instead of my body, and letting the shame, grief, and trauma spiral me down. That's what's unhelpful for me."
- "I keep a list of simple sentences next to my bed: 'This is hard, but it's not hopeless.' 'My illness may not change, but my experience of it will.' 'May I be gentle with myself in this moment.'"
- "Another thing that doesn't work for me is beating myself up for being sad or disappointed. You have to feel your feelings! And yes, distraction is great."
- "I remind myself that I'm feeling this right now, but it won't last. We never expect that the good feelings will last forever; we don't need to worry so much that the bad ones will. All feelings arise and pass."
- "If I can't be kind to myself, I reprimand myself like a child. There, I said it. I have to give myself a break."
- "When I accepted my illness, it was not giving up. It freed me to be able to enjoy the moment for what it is. My life has been much better."
- "'Acceptance doesn't have to mean agreement.' I accept I'm ill; I don't agree that it's fair."
- "I think acceptance is for accepting where you are in your illness journey in the present moment, and acknowledging that it may wax and wane over time."
- "Radical acceptance during grief is life-changing and so helpful."
- "Thank you, Timothy, as always, for reminding us that acceptance is not resignation."
- "Love the 'boundary of power.' It's a balance between optimism and realism, and as Timothy said, it is a practice; I'll never be done."
- "My therapist sent me to a six-month grief group because I had experienced so much loss with this illness. Speaking only for myself, it helped a lot."
- "I have to limit my emotional expression. Even too much belly laughing can bring on PEM. I sort of time myself: I track my symptoms during a good cry to make sure I don't go too deep and trigger PEM."
- "I've started trying to do one 'new' thing every day. Sometimes it's just listening to a new song, trying a new puzzle, or a new app."
- "You can only do what you can do. Do what feels right to you. Protect your peace. Protect your health."

- "I'm the oldest of four. I just need to be 'selfish' and take care of myself. My health is too important to me."
- "The self-identity struggle when helping family feels like part of who you are, and then you just CAN'T. As the eldest daughter, I always assumed I'd be the one in the role of helping. It's really tough to feel helpless."

Tiny Triumphs

- "I had a neurology appointment for migraines, and the nurse practitioner actually knew a little bit about ME/CFS. She noticed my armband, knew that graded exercise was not recommended and that pacing was the way to go, and asked me questions to learn more for other patients. First time in over a decade seeing a provider with some understanding and real interest in learning more, so refreshing after so many dismissive providers."
- "I got my flu and COVID shots last week and only crashed for 3 days afterward. I'll take that as a win."
- "My insurance appeal was approved, so I can go back on a medication that was working well for me."
- "I was able to leave my house on the long weekend and change the location of where I lay down. It was great to be in a beautiful place different from my sofa and bed."
- "I got a real bed, which is a huge upgrade from my parents' couch! I've been bed-bound for several months and this is a big relief."
- "I'm feeling more like myself. I do a lot of tracking (symptoms, what works, what doesn't, what crashes me), and some new and shifted strategies have been giving me fewer crashes and more energy."

Resources

- Timothy Weymann's website: https://www.timothyweymann.com/
- Color Communication Cards: https://batemanhornecenter.org/wp-content/uploads/2022/01/Color-Communication-Cards.pdf
- Kristin Neff self-compassion resources, books, and short guided meditations: self-compassion.org
- Stickman Communications – illustrated cards for explaining chronic conditions: https://www.stickmancommunications.co.uk/shop1

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

Chronic Illness Therapist Directory

- https://www.thechronicillnesstherapist.com/directory

Open Path Collective

- Helps connect people with lower-cost therapy options:
    - https://openpathcollective.org/getstarted/

ME/CFS Writing Group

- https://pillowwriters.wordpress.com/

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 1st and 3rd Tuesday at 1 pm MST
    - https://batemanhornecenter.org/events/
- Black COVID-19 Survivors
    - https://www.facebook.com/groups/bcsalliance/
- Brain and Spine Group for Zebras
    - https://www.facebook.com/groups/brainandspinegroupforzebras
- 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/
- Mass ME Gen Z & Millennial Northeast Meetup
    - https://form.jotform.com/260346468999174?utm_source=newsletter&utm_medium=email&utm_campaign=april-2026-newsletter
- #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/
- 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 with 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 on 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 on the third Saturday of each month at 10:30 p.m. PT / 1:30 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.