# Support Group: Surviving Invalidating Relationships and Experiences

*March 11, 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, started the session with explaining that by becoming sick with a chronic illness we become a minority (if we weren't already) based on the prevalence rate of these conditions. This means that we can face similar things that other minorities may experience such as prejudice, discrimination, and ignorance. One component of that is having what can sometimes be an invisible illness that's not obviously manifested.

The following questions were used to guide the support group discussion.

**Discussion Questions**

**1. What are some of the complications in relationships you face while having (invisible) chronic illness?**

**2. What helps you cope with prejudice and discrimination in managing chronic illness?**

**3. What communication/relationship skills do you want to keep developing to help you cope with invalidation?**

**4. What are ways you feel included, seen; ways you have a felt sense of belonging?**

**Timothy's Shared Wisdom**

- It's hard to be a 'not' with regards to telling people what we do. We can tell people what we can't do but perhaps adding things we do within our illness limitations such as where we spend our attention and labor can support conversations.
- When he was first ill, Timothy sent a mass group text to family that explained what we was capable of doing, what he couldn't do, and what he would appreciate from them.
- It's important that we take ownership for our wants and needs and our limits. Then honestly express them and ask for what we want to really set the boundaries and tone of the relationship.
- When struggling with how to say 'no,' Timothy suggested saying something like, "Because of my illness I have to say no this time, but I always love being asked. Please don't stop asking. It makes me feel included."
- Oppression internalized becomes depression. In the face of ableism, it can be important to be self-advocates to stand up for ourselves because if we don't it can be internalized and become anxiety, depression, or self-condemnation.
- Problems can come when our limitations bump up against other people's limitations. In stressful situations existing problems such as deficits in relationship skills and communication skills either within ourselves or other people come to light. This makes it important to label the deficits and not internalize them. An example could be, "Susie struggles to listen to everybody, not just me. So, I know it's not about me or my illness."
- People in our lives have to adjust to our "new selves." They also need the space to grieve. We must remember that not all relationships will be sustained through the transition that we experience when developing a chronic illness. A big part of the grief process is the reinvestment stage. During this stage we have the opportunity to focus where we can reinvest to have our needs met since they won't come from certain people anymore.
- Keep identifying and challenging fears. Not everyone will behave like a rejecting family but when we've been traumatized sometimes our brain won't differentiate from that so we can disproportionately mistrust people. Be mindful of slipping into all or nothing thinking. Extreme thinking doesn't recognize nuance.

- Hopelessness in unsolvable agendas can be productive. If we have a family member or friend who is in denial about the vulnerability of the human condition that is not our issue to solve. Sometimes instead of experiencing grief and accepting the limit of someone or something we keep pushing and ending up in frustration. There are people who work to understand and don't use bootstrap language which isn't helpful, or reality based.

**Participants' Verbal Comments**

- Participant shared that he struggles with knowing what to say when people ask him to do things, and he has to keep saying no.
- Participant shared that because of her limitations it can feel like the friendship is more focused on her and her needs, so she works hard to also focus on the needs of others and show up for them in ways that she is able.
- Participant shared that she keeps written cards in her purse that are positive affirmations about being enough that she can look at when experiencing dismissal and misunderstanding from others. She also sends people the link to the ME/CFS Guidebook to help them understand what she must do to manage her illness.
- Participant suggested that putting the illness experience into writing can be a way to share what your life is like with others. She has found that putting it into words has given her credibility that it wouldn't otherwise have had.
- Participant shared that she is new to realizing what is happening with her health and her family doesn't trust her as a reliable narrator for what she is learning about ME/CFS.
- Participant shared that she struggles to find the balance between having relationships and getting things done without crashing. When she gets help from someone it saps her energy. The people in her life only see her when she looks normal and not when she is in a crash, so they don't know what her life is really like.
- Participant shared that he can sometimes be too weak or cognitively challenged to describe his symptoms and ask for what he needs from healthcare practitioners. Having a few people who love him and understand helps him cope

with the prejudice and discrimination he experiences. He lost friends but built relationships with people he met in an online community.
- Participant shared that she feels seen when there is an effort to survey access needs for everyone. She appreciates pauses and time to process. She enjoys connecting in social justice and chronic illness spaces that allow for reciprocity.
- Participant shared that writing articles and posting them on her website to direct people to has been helpful. It saves her from constantly explaining answers to questions.
- Participant shared that she has become traumatized from the rejection and lack of understanding from her family. This has caused her to be afraid of talking to new people.
- Participant shared that he is mostly bedbound and has found enjoyment in online communities such as:
    - Meditate Together
    - London Writers Salon
- Participant stated that it's important to be there for ourselves.

**Participants' Comments from the Chat**

- "When you are finally able to have a visit don't focus on how long the visit is. Go as long as you comfortably feel you can. 10-15 min can really help your mental state. Just thank them for the visit, tell them you really appreciate it, but you'll have to cut it short. Hopefully you can build up to 30min-1hr. I always tell myself this is worth all my spoons as I rarely do visits."
- "One of the core truths I repeat to myself is: 'What works for you does not work for me. We are different and I'm okay with that'"
- "I love 'I'm important and I'm valid and I am enough'"
- "Answering the 'So what do you do' question: my plan is to change the tense. So, to say 'I'm taking a break right now, but I *have been* [doing my most recent job].' That still lets them know what kind of work you do/did, and glosses over the disability aspect at first."
- "I wrote all my friends cards saying thank you for all their support, trying to frame it in a positive way and acknowledge their support."

- “Two of my daughters watched “UNREST” and “FORGOTTEN PLAGUE” with me. Unfortunately, my third daughter has consistently refused to watch those documentaries or to educate herself about my wretched illness: ME/CFS.”
- “I have successfully educated my siblings using the BHC resources. They were surprisingly interested, so I feel very fortunate. My friends have been more challenging, but to be honest, I haven’t tried as hard. I do get left out of activities, but they say they don’t want to make me feel bad by inviting me when ‘they know’ I can’t go. They are truly being kind in their own way.”
- “I recently started simply saying that I have Myalgic Encephalomyelitis, a post-viral syndrome. Neuro-inflammation. PEM. Lots of jargon. Nothing about CFS anymore. I am finding people can take that in with more seriousness and understanding.”
- “I wrote all my friends cards saying thank you for all their support, trying to frame it in a positive way and acknowledge their support.”
- “Sometimes, if I just can't get through to someone, I try to have compassion for where their mindset is, how strong the social conditioning is around health, wellness, and productivity. It's not my problem how someone reacts to me and my condition, whatever it provokes in another. My spoons are precious, and I don't always feel the need to push back. Save it for when/where it's needed.”
- “Try this kind of reply to your Doc: ‘It would be great if I felt as good as I look, wouldn’t it?! But I am barely managing to complete a few activities of daily living that people in good health do without thinking, though, like taking a shower and doing my dishes if I prepared my dinner from scratch. It just goes to prove that, no one, even you as a doctor, can see my invisible symptoms that disable me so badly.’”
- “Sometimes I write letters of grief about it, and it helps me to both honor and release the emotions. I've never given them the letters, but it feels empowering for me and if I ever did feel like one day I could share some of those things with them, I'd have them kinda thought out already.”
- “This Podcast Will Kill You has a great episode on ME/CFS (Ep 137). I shared that with my parents. For people who would rather listen than read. https://thispodcastwillkillyou.com/2024/04/16/episode-137-me-cfs-whats-in-a-name-a-lot-actually/”

- “I appreciate these quarterly talks. A live session is coming up tomorrow (recordings are posted YouTube). Might be of interest to folks here: https://www.mindbodysolutions.org/events-workshops/yoga-disability-transformation/”
- “On Netflix is a great movie/documentary *The Remarkable Life of Ibelin*.”

**Tiny Triumphs**

- “Went to bed on time!”
- “I got some work done on my taxes this morning.”
- “I got here on time!”
- “Got a decent night’s sleep!”
- “Noticed when my brain was tired and stopped what I was doing AND I finished my taxes this weekend.”
- “Have avoided sugar today.”
- “Pacing with one activity a day - not overdoing it and cancelling appointments if necessary.”
- “Stepped outside to soak in the sun for a bit!”
- “So glad TT is back. I was able to go to get groceries at a few different stores a few days ago and I didn't crash!”
- “Am treating myself with love, care, acceptance.”
- “I went on a picnic outside with my daughter!”
- “Went outside and got a haircut and stopped on a place on the way back! Two things in one trip 🙂”
- “I took a great nap yesterday and think I'll take one this afternoon as well!”

**Session Resources**

- Life with a Low Battery: Living with ME/CFS (great to share with loved ones who don’t understand)
- BHC’s ME/CFS Guidebook
- BHC’s Communicating with Loved Ones
- Information about ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) for Health Care Providers

- The Germiest Place on Earth (blog post on BHC website): https://batemanhornecenter.org/the-germiest-place-on-earth/
- Long COVID Musings YouTube channel: https://www.youtube.com/@LongCovidMusings
- *Unrest* documentary: https://www.youtube.com/watch?v=XOpyLTyVxco
- #MEAction: https://www.meaction.net
- Spoon Theory: https://en.wikipedia.org/wiki/Spoon_theory
- Living in a Body substack: https://halwalker.substack.com/
- Disability resources:
    - https://www.ssa.gov/disability/professionals/documents/EN-64-128.pdf
    - https://howtogeton.wordpress.com/social-security-disability/
    - https://www.peopleshub.org/trainings-and-offerings/community-care-clinic-for-disabled-and-chronically-ill-movement-folks
    - https://www.longhauler-advocacy.org/
- Health Rising blog: https://www.healthrising.org/
- https://longcovidland.com/
- Stickman Communication Cards: https://www.stickmancommunications.co.uk/?srsltid=AfmBOoo3yIzZabbFa6J5ukm07bSIo8nGlLo5amPnnVdIzTDytWheQ6Ay

## 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 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.