Support Group: Freedom from Thinking Traps Amidst Chronic Disease

December 16, 2025

Announcements

- Subscribe to emails: https://batemanhornecenter.org/outreach/newsletter/
- Clinical Care Guide: https://batemanhornecenter.org/clinical-care-guide/
- Support BHC's mission: https://givebutter.com/BuildingAccessNow
- NEW BHC online event schedule beginning Jan 2026
  - 1st Tues: Support Group
  - 2nd Wed: Coffee with a Clinician
  - 3rd Tues: Support Group

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 a thinking trap is a way of thinking that keeps us trapped in increased emotional suffering. Thinking traps affect everyone, not just people with chronic illness.

Guiding Questions

1. In what ways do you feel you get mentally stuck in the context of facing your illness?
2. What kind of thinking are you finding to be unhelpful?
3. What ways have you changed your thinking to help you face your illness?

Timothy's Shared Wisdom

- We can be caught in a trap of catastrophizing and jumping to the worst-case scenario when projecting into the future.
- When we are caught in thinking traps we can have very narrow definitions of success. We can expand our definition of success and what it will look like with chronic illness.
- People who are resilient focus on what they can control. When we focus on things we can control our resilience level goes up.
- We are invited to confront society's denials about our disability and at the same time confront our own denials about disability and how those can be parallel.

- We can be more assertive in conversations about our illness and ask for what we want in the conversations by being more direct with our needs in conversation. We can try not to personalize others' feelings and reactions to our illness.
- We can be self-forgiving because our capacity can change as we go through our illness.
- Mindfulness is the intention of our attention. By being more intentional regarding where we place our attention we can avoid thinking traps.

Participant Verbal Comments

- Participant shared that they are in a crash and recently had a mass found in their lungs. Their first thought was to give up and think of the worst-case scenario, but they are trying to reframe their thoughts into surrendering into the limitations and resolve into pushing for healing and being the best, they can be.
- Participant shared that they are struggling with doing basic mental tasks and physical tasks and feel like they are stuck and not growing. They are struggling with not growing into hobbies or knowledge or creativity.
- Participant shared that they find themselves spiraling multiple times a day and have to stop themselves. They are finding that when they focus on the "why" they start to spiral. In comparison, if they focus on what they can do about it and go on living in a new way they can find meaning and stop the thinking trap. They find hope in research and what they have been able to teach those around them, as well as the journey they have been on.
- Participant shared that they have felt very stuck lately dealing with the throws of ME. They are struggling with the fact that they are young and get caught up comparing themselves to others their age. They are stuck in this thinking trap of the struggle of living an unordinary life.
- Participant shared that they have been struggling lately with their new job and balancing society's demands and their own capabilities.
- Participant shared that they get stuck in thinking about their past capabilities and this can cause them to crash out more due to this thinking trap.
- Participant shared that it is so hard to focus on things that they can control when there is such a lack of understanding with this illness. They also relate to painful boredom and being stuck in past capabilities. They are stuck in a thinking trap

where every conversation they have can come back to their illness and have received feedback that people don't want that to always be the topic. They are struggling to change their patterns because this illness is all encompassing.

- Participant shared that they get stuck in the pattern of getting ready to add more onto their plate and into their lifestyle the minute they see any improvement. They are trying to focus on making sure that they can manage the place that they are currently at before taking more on.
- Participant shared that they went through a lot of anger about getting sick and feeling like it happened right when their life started "going well". They struggle with thoughts about how they had to change their values and what they identify with. They try not to focus on being cured and try to focus instead on what is okay and the people that do get it in their life.
- Participant shared that we need to lower our expectations at times when it comes to others' understanding of this illness. We set ourselves up for lots of disappointment if we don't understand that others will have a hard time understanding what we are going through because they are not in it.
- Participant shared that managing their expectations has been beneficial while also focusing on the fact that they can live a life worth living.
- Participant shared that they searched for support groups so that they weren't putting their entire emotional burden on the people closest to them. They shared that support groups help them in feeling less alone and helps them have support from people outside their immediate circle of support.
- Participant shared that there isn't always a lot we can do to stop the thoughts and traps that come with them. But coming up with a strategy to keep tabs on their thoughts to try and control them is their best advice and approach to thinking traps.

Participant Comments from the Chat

- "Thinking about things in terms of what I 'should' be able to do or used to be able to do are not helpful. thinking about things I can do and breaking things into smaller tasks and counting each one as a triumph is helpful."
- "Question 1: thinking that I am limiting myself, that this is in my head, that it really isn't that bad. I know and have evidence that these three things are not true, but that does not stop the thoughts."

- “I love growing via the wonderful online lectures available from:”
    - SmithsonianAssociates.org
- “A big help for me is flipping the script … changing the lens thru which we view life. Try to look for things we can do … no matter how tiny … that can help. Also with that mindset, CELEBRATE EVERY WIN!!!”
- “Question 1: In what ways do you feel you get mentally stuck in the context of facing your illness? -- I am an ADHDer and I get hyper focused on reading too many scientific publications, which is sometimes helpful, because it fits with my interests, but my other interests get neglected then (I am very monotropic), and I cannot really steer my interests.”
- “I feel in control over my mental and spiritual growth. I may not have grown this much if I hadn't been forced to lay down for 4 yrs with tons of time to reflect.”
- “Woof that one sentence… boredom, fear of relying on others, not having systems to support us. SO relatable.”
- “Today I found an old note from counseling ‘Turn problems into goals.’”
- “I realized I was comparing myself to my former self whereas my manager only knows me now, which has helped me feel a bit less self-conscious.”
- “It’s so difficult dealing with the brain fog when you’re someone who is used to functioning well.”
- “I always plug this blog. I got SSDI first time around with the help of this. It’s pretty big so there might be some forms that are helpful for you too.”
    - https://howtogeton.wordpress.com/social-security-disability/
- “I found this website that has a list of accommodations employees (with long covid/MECFS) can ask for. I find it super thorough! Not sure if it's helpful but just thought I'd pass along.”
    - https://askjan.org/disabilities/Myalgic-Encephalomyelitis-Chronic-Fatigue-Syndrome.cfm
- “I’ve given myself the gift of patience in recognition that things now take way longer to complete than they used to.”
- “I saw it described well online: Applying for disability in the US is like being put on trial for a crime you never committed.”
- “Disability makes people uncomfortable, but I don’t think that’s on us to change. It’s a part of our every moment, and it can be a part of something we discuss with those close to us. But, it’s tough when people don’t understand!”

- "Everyone has different capacity of understanding and empathy. And you have no control over their capacity. I have had to learn who can handle what and be supportive and who just doesn't have the capacity. That doesn't make them bad or mean, and most people do not do this intentionally, it is just what they are able to handle and unfortunately empathy is very hard and uncomfortable for a lot of people."
- "Accept that others are human and have fears and difficulties. No one would want to go through difficulties so it makes people uncomfortable having evidence that something can come so close to them even if it's not contagious."
- "I recently read *How To Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers* by Toni Bernhard…. because so many of you referred to it here. I found it very helpful and I recommend it - especially in relation to today's topic."
- "Whoa that's so true!! Not personalizing it when others can't meet your needs even when you are assertive and speak your needs is key. They are on their own journey."
- "I'm micro-dosing hope."
- "I apply a sort of spoon theory...I just won't spend precious energy and time on the wrong relationships or people. It takes time to get to that point, person by person."
- "My sister has a quote on our fridge... *Don't let what you can't do stop you from doing what you can do.* It's really helped me with feeling trapped in this body."
- "I refuse to use any energy on anything negative or things I can't control. I have very limited spoons each day... I need to use them on stuff that will benefit me."
- "I lost a range of people, from acquaintances to immediate family and close friends I've had for years. Kind of like what Tim said, sometimes our disability is revealing of the patterns in our relationship."
- "For me I am focused on living in the present moment!! That is all any of us has...this moment. I surround myself with comfort! My room is cozy. My cat is so loving. If I want ice cream every night it's okay. I practice gratitude and find joy in little things. Mindfulness! Gaslighting can make me feel intense anger but I rise above it to my safe place where my validation comes from myself."
- "One day at time. Or sometimes one minute at a time. Reading stories of people who have found ways to improve and cope with their illness can help. The first

year is hard and chaotic as you learn to adapt. Hang in there; you never know when things might change for the better."

- "I just started using that kind of vibe of a broken leg or broken --- to make myself realize I can't do what I can't do. Maybe it's invisible to us too sometimes. It was easier seeing a surgery scar or a cast or things like that, while being stuck at home."
- "We can still do many things we were able to do before. We just happen to do them at a snail's pace and on a completely unscheduled timetable."
- "Here's one book:"
    - https://www.amazon.com/How-Many-Marbles-YOU-Have/dp/1499094450
- "*Why does Mommy Hurt* and *Some days A tale of love, ice cream and mom's chronic illness* are the two that I found. One is based on MS the other Fibro, but I just say 'Chronic Illness' instead. They are both written from the kid's perspective."
- "Living like my cat. Nap when you 'feel' like it. Take your time getting to food. Let someone else clean your bathroom if you can. Demand peace of mind, affection and attention on your terms."
- "I have chronic Long Covid and I tell those with ME/CFS to tell their friends and family that ME/CFS a is very much like Long Covid. Because Long Covid is newer and received more media attention, people seem to have a bit more compassion, patience, and understanding."
- "A caregiver's frustration is valid too communication without judgement and defensiveness is important."
- "And if you haven't seen it, *How to be Sick* is a little book that is very encouraging and helpful in reminding us to stay in the moment."
- "I have a similar history to yours (many years undiagnosed, then slowly learning) and relate a lot to what you said. One thing I've found helpful has been to reexamine some of those earlier years in writing and therapy. From my current vantage point it becomes clearer how some patterns formed that I then need to change - but also that I really couldn't do it at the time, and recognizing that turning things around is a long term work - I guess it ties in with the self forgiveness Timothy mentioned."
- "I had to dig up this quote I'd found on Pinterest (posted by 'Chronic Perseverance' but attributed to 'Unknown'): *Being young and sick is sorta like being elderly, except we lack the reflection on all the great times and great things we did long*

ago. Instead, we watch our peers make the memories and strides they'll look back on fondly, bitterly observing and praying for our chance. With chronic illness there's definitely grieving the person we thought we would become, but hopefully we can achieve the paradigm shift in our thinking and focus on the things we ARE able to do and accomplish in our new normal, and realize we can still live a fulfilling life!"

- "I recommend Elizabeth Lesser's book *Broken Open*. She founded The Omega Institute in NY. Check out their site for online groups. I felt broken through most of this until I remembered the book and now I feel broken open. I am me but different. I have evolved into a stronger woman grounded with new priorities and goals."
- "I created a 'what to do when I am unwell' cheat sheet and it lists my main symptoms and the tools I've learned that help each symptom and I shared it with those closest to me. So, when I have brain fog or difficulty asserting myself or asking for help, my loved ones have some clues as to what they can do or suggest to get me to feel better. Hope that helps someone."
- "It's challenging, but I try to hold acceptance of my illness and hope for improvement in my mind at the same time. They don't have to be mutually exclusive."
- "I use Axel Barr's to keep my thoughts up and above. It's so helpful."
- "Psychologytoday.com is a great resource for therapists. You can search by location and specialty and telehealth options. It's where I found mine."
- "I find that when my energy is low, my brain's messaging becomes more negative. I've learned to tell myself, literally out loud, 'This is not you. This is low energy affecting your brain. Rest!'"
- "Last week when I was feeling discouraged I decided to write some Haikus. The creative process was amazingly therapeutic."
- "Buddhist belief that suffering is caused by attachment we are attached to how we think things should be if we let go of attachment we suffer less."
- "I no longer compare myself to my friends and family. Instead, I compare myself to my cat, who sleeps or rests nearly all of the time."
- "I have a picture of Garfield in my recovery journal with a reminder to 'be more Garfield' - rest and eat lasagna and find joy."
- "She has several books we can relate to:"

  - http://tonibernhard.com/
- "PSA that we are more likely to get scammed via text/phone due to brain fog. I unfortunately fell for a scam last weekend where someone convinced me they were texting and calling on behalf of my credit union. I learned that I ALWAYS need to stop and get help from someone I can trust without cognitive impairment."
- "MEAction has a campaign right now to collect signatures for a petition. The goal is to qualify people with ME and long covid as 'medically frail' and exempt from Medicaid work requirements. Thanks for taking action to protect our access to Medicaid!"
  - https://actionnetwork.org/petitions/freakin-frail?source=direct_link&
- "The Chronic Illness Humor account on Bluesky is good for dark humor, when that's what you need."

Chat Response Ideas to "How Are You?"

- "When asked 'How am I doing' I say 'I'm upright'"
- "Thanks for asking. I'm glad to see you. How are you?"
- "(Monty Python Voice) Not dead yet!"
- "I respond with the question: Do you want the socially acceptable answer or the honest one? I let them choose how much they want to hear, and it's kind of like, maybe don't ask that question if you don't really want to know."
- "I use neutral stuff, like I'm enjoying the weather, or read a good book or looking forward to whatever, not health focused."
- "When people say 'How are you doing', I say 'I'm doin'"
- "'up and not crying' is a fav."
- "My go-to response is 'surviving but not thriving!'"
- "How are you response: still here"
- "How am I??? Lousy, but thanks for asking."
- "I'm having a tougher today, struggling a little … terminology like that."

Tiny Triumphs

- "I stood up for myself in a group meeting (member for 7 years) where I was bullied and disrespected. I set a boundary and likely won't return."

- “I was able to go to 2 appts on consecutive days (I didn't have a choice in order to get them in before the new year) without crashing hard.”
- “I have had three successive nights of good sleep. This does not seem like a Tiny Triumph as I have been struggling with sleep for years.”

Resources

- BHC diagnostic and disability resources page. It's directed to medical professionals but can be helpful for patients too:
  - https://batemanhornecenter.org/providers/top-resources/
- BHC's Crash Survival Guidebook is a great all-around resource for patients and their family members:
  - https://batemanhornecenter.org/education/mecfs-guidebook/
- Caregiver Support Groups:
  - Caregiverwisdom.net
- What I Want You to Know resource:
  - https://batemanhornecenter.org/wp-content/uploads/filebase/Chronic-Illness-What-I-Want-You-To-Know-Fillable_2.pdf
- https://www.goodreads.com/book/show/41016873-full-catastrophe-living?ac=1&from_search=true&qid=9MiixAzAZF&rank=1
- Timothy’s Website
  - https://www.timothyweymann.com/

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

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/
- #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 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 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.