Support Group: Chronic Illness: Facing Limits and Losses (Moving through Grief)

February 3, 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/
- 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, introduced the topic by noting that grief is a recurring and often cyclical experience. In the context of chronic illness, grief is described as ambiguous, meaning individuals may not fully know what has been lost, how long the loss will last, or whether what was lost will ever return.

Guiding Questions

1. What are you currently grieving in relation to your chronic illness?
2. What are the ways you've reclaimed (in whole or in part) what you've lost?
3. What helps you let go and move forward?
4. How are you moving beyond loss to acceptance, adaptation, and reinvestment?

Timothy's Shared Wisdom

- Chronic illness can be especially destabilizing when identity is closely tied to abilities or roles that are lost. We can anchor our identity in more stable, underlying values such as connection, learning, purpose, or creativity. By focusing on these deeper values, we may find some protection against the pain of loss and discover new, accessible ways to express what matters most within our current limitations.
- If you are in a state of mourning, it can be helpful to look back on a time we went through a different loss and draw on what helped us get through that time. This can help to reorient us and help us navigate grief.
- Loss is inherent to being human. Everything's constantly changing, and if we're able to normalize that more, it doesn't take away the pain of the loss, but it can soften it.

Participant Verbal Comments

- Participant described grief as an ongoing process that resurfaces each setback or new awareness of loss. While there has been some adjustment over time, grief remains constant, moving in waves between acceptance and sadness. Having small, manageable hobbies has made a meaningful difference, providing something to look forward to during periods of improved energy. Creative activities and music are approached flexibly, with abilities varying greatly from day to day, which can also bring sadness.
- Participant described that recent changes have raised concerns about potential loss of mobility in the future. They expressed mixed emotions of worry and unhappiness about what may lie ahead, alongside small moments of encouragement when daily activities feel easier.
- Participant shared that grief has been a constant presence for several years since recognizing long-term illness. They described ongoing losses, including physical and cognitive abilities, work and career, social connections, and aspects of family life, leading to anger and frustration. They emphasized the importance of not being defined by work and the need to reinvent identity over time. They also described adapting creatively by shifting to smaller, more manageable forms of art, viewing this as a symbolic way of adjusting, staying present, and continuing forward despite ongoing loss.

- Participant described grief that has fluctuated over time, with a recent surge tied to realizing the loss of intellectual engagement in their career. They reflected on deep enjoyment and identity connected to their former professional role, and the sadness of recognizing that while they can still read or learn about the field, they can no longer actively practice it, marking a new and painful loss of professional identity.
- Participant described mourning changes in mobility, independence, family roles, and the ability to live the life they had envisioned, including the shift to using a wheelchair and relying on family care. Drawing on coping skills developed through earlier grief, they emphasized not giving up, focusing on breath, building and maintaining community (now largely virtual), and deepening spirituality. They described ongoing efforts to adapt through meaningful work, creative problem-solving, nervous system regulation, journaling, structured rest, and maintaining a list of enjoyable, accessible activities.
- Participant shared that they have grieved many losses, including having to stop working and losing the sense of being capable and needed. While they have largely come to terms with that, they are now grieving connection, fun, friendships, and cognitive functioning. They described practicing acceptance as central to coping, choosing not to compare themselves to others, and recognizing that loss is a part of life, though chronic illness has made it more sudden. Pacing, meditation, and journaling help them process emotions.
- Participant shared that grief and chronic illness have been intertwining themes in their life for many years. They reflected on the guilt that can arise when partners and loved ones also carry the impact of their losses. At the same time, they are beginning to experience small improvements in quality of life and are learning to hold both grief and gratitude together. For them, coping involves accepting the duality of loss and appreciation of coexisting and intentionally recognizing achievable moments of capability.
- Participant shared that receiving multiple new diagnoses brought relief and grief. They described intentionally reclaiming joy rather than focusing solely on survival and medical tasks. They are working to balance necessary care with visibility, creativity, and small, meaningful communal experiences, recognizing that true acceptance involves holding both grief and hope at the same time.

- Participant shared that since becoming ill after COVID, their world has narrowed to their bed and a dark room. Their child was an infant when they became sick and had only known them this way, which brought deep grief and heartbreak. They described profound loneliness, loss of identity, and the pain of friendships fading due to others' lack of understanding about the physical limits of their body. Being mostly unseen and housebound intensifies the isolation, and mornings feel especially heavy. Their grief centers on the life they once had, the parent they hoped to be, and the uncertainty of how long this loss will last.
- Participant shared that their experience of grief is complicated, as Long COVID led to scans that unexpectedly revealed lung cancer and post-polio syndrome, bringing both life-saving answers and new losses. They described holding gratitude and grief simultaneously, feeling thankful for early cancer detection, medical care, and improved breathing support, while also mourning physical limitations, crashes, and the cumulative impact of illness over a lifetime. They emphasized the importance of fully feeling emotions without judgment, setting firm limits with others, and protecting their energy. They focus on intentionally choosing meaningful experiences. Alongside personal health challenges, they are also navigating the realities of aging and the deaths of friends, underscoring how layered and ongoing grief can be.
- Participant shared that they are grieving many losses, particularly the loss of their cognitive sharpness. They described once being quick-thinking, highly informed, and someone others relied on for answers, but now struggling with memory, focus, and sustaining conversations due to brain fog. They shared the frustration of needing to limit emotional intensity to avoid crashes. The cumulative losses have led to profound loneliness, and maintaining positivity often feels exhausting.

Participant Comments from the Chat

- "I am grieving being able to walk and hike. Before COVID, I walked 4 miles every day. Now I can make just one mile."
- "I am heavily grieving my old self, who could do things and go places without extreme fatigue and struggle, and who could think about the future instead of just surviving the day."

- "Grieving how it's hard to maintain relationships."
- "I'm grieving loss of career and 2 diagnoses I got this year that are likely 20 years in the waiting...but I didn't know till this year, just kept getting the wrong answers."
- "I just started disability retirement but I'm 39 not retirement age grateful for the coverage but grieving what I had imagined my career to be."
- "Mobility aids will make a HUGE difference. and there's no shame in that."
- "I grieve being unable to run, cook, and being able to stand during conversations. I am thankful that I can set limits and avoid doing things that I don't want to do."
- "I want to highly recommend the 'Wearable' from Visible. I started using it 3 weeks ago, and it helps so much with pacing."
- "I am grieving dancing and hiking right now. To find joy I have done some little things…window bird feeder, squirrel feeder on the fence, art, movies, and I went to a Tom Petty Tribute Band concert recently with my earplugs and got a seat where I could still see without standing."
- "I'm grieving spontaneity. I'm sick of micromanaging every aspect of my life. 5 minutes of freedom from heavy consequences is my dream."
- "You are more than a job, you are your heart, your talents, your creativity, intelligence."
- "I should probably grieve more, because I am ambiguous as I cling to social contacts and don't dare to stop them when I notice impairments…I would grieve hard if so! But I lost dating contact because I couldn't be so close, that hurt. I grief my social status, too: will be a pensionist with 43 years soon and lose my financial independence with social welfare hopefully."
- "I am currently grieving how my illness is affecting my family. Specifically, my husband is an extremely ambitious, capable person, and due to my illness, he's having to massively temper his career and personal goals to step in to care for me and our young son. I also grieve that my toddler doesn't have the mommy I wish I could be for him."
- "YES!!!!! Journaling, meditation, deep breathing and pacing are key."
- "The part I don't understand is what to do with that grief? I do understand how to do other things, find new ways to look at things, other things to do or enjoy.....

but that "box" of grief... where do we put it where does it go other than aside, while we work on redirecting?"

- "I've found a few online instructors with very gentle movement geared towards people with chronic conditions. I like Chimera Health, Jeannie Di Bon, QiYoga, and this page, Embautied (https://www.youtube.com/@embautied). Short, low/no impact."
- "I love this quote: 'In a culture obsessed with productivity and achievement, choosing to rest is one of the most proactive and courageous acts a person can make. . . To rest in the context of chronic illness demands the endurance of immense grief.' However, I yell at myself for continuing to grieve after living in this current ME episode for seven years. Will I ever be done with grief? I feel so stuck."
- "Toni Bernhard, author of, *How To Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers,* and ME/CFS person writes: 'To me, broken-glass practice is particularly helpful in… a change in our lives that keeps us from participating in or enjoying activities that we may have counted among our greatest joys. I find comfort in contemplating that my ability to participate in these activities was already broken, in the sense that this change in my life will befall everyone at some point and quite possibly by surprise. This is simply how and when it happened to me.' p.38"
- "No paywall access to NatGeo article on link between LC and hypermobility."
    - https://archive.ph/QoEmv#selection-4823.0-4830.6
- "What if I accept where I am at, but my family hasn't accepted it? My family sees cognitive impairment as a character flaw instead of a symptom of ME. They say if I'd push harder, we can move on to our dreams while my life is always carefully pacing. I realize they are in grief, too. I try to have grace. It feels like a reflection of medical PTSD, but in my safe place."
- "Internalized Ableism…. WOW. Now I have a name for it!"
- "We grieve things our whole lives. There are all kinds of losses we go through living life."
- "Also grieving loss of healthy relationships. so overstretched & struggling here with my condition and elderly mom that relations are strained. It's only going to get harder over the next few years. My healthy sibling lives an extremely full life

of freedom and has everything in place, yet all the burden falls on me because I live with my mom. The dynamic and stress are causing strained relationships, yet the sibling who does nothing but phone calls get to be the 'good one and the fun one.'"

- "I found this book very helpful, *Grace Disguised: How the Soul Grows Through Loss*, by Jerry Sittser.
- "Showing up is a tiny triumph. It may not feel like much but sometimes it's *everything*."
- "Chronic Illness Humor on Bluesky will make you laugh with its dark humor."
- "Facebook groups I'm part of: Beat Long Covid with a smart watch, Dysautonomia International- Ontario support group."
- "This resource is a bit off topic but for some people creative activities are something we can still do from bed. I recently started The Artist's Way and I think it has been helpful to encourage the creative things that we are capable of despite our limitations with MECFS."
- "I use the Vision Monitor to help with pacing. If my emotions are high (Bad or good) I use up a lot of points even if I am just sitting in a chair. It is good to have objective evidence."
- "My mantra is 'This too shall pass.' I can get through the next 15 minutes, and the next 15. If I can't do that I can get through the next 5 minutes and the next 5."

Tiny Triumphs

- TT: I've started short-term therapy.
- TT: Got birdseed for the feeder. Now to put it in!
- TT: I completed USA Social Security request that took me 11 days due to PEM. It probably would have taken an hour before becoming ill, but I did it with help from my family.
- TT: I've updated and edited my CV and am feeling better about trying to find a freelance historical research or copyediting project
- TT: For the last 4 years I've overseen programming the door locks here at my condo. I've been feeling overwhelmed, so I told the HOA they needed to find someone else to do it. I spent an hour on Saturday teaching them how to program the locks so now I'm done with it. I feel so much better.

- TT: I GOT CATS! And their purrtfect.
- TT: Tomorrow I will attempt to start physical therapy, which I haven't been able to do because of fatigue. I still don't have the energy, but I need to try it.
- TT: I've started neuro physio
- TT: I am now dating someone with two chronic illnesses. He gets it.
- TT: after 6 years of LC, I finally have a LC internal medicine doctor!

Resources

- Timothy's Website:
  - https://www.timothyweymann.com/
- https://badbitchbookclub.com/
- The BHC Crash Survival Guidebook is a great resource for managing your energy envelopes:
  - https://batemanhornecenter.org/education/mecfs-guidebook/
- New Your City WhatsApp Group
  - https://chat.whatsapp.com/BwttGeWs8OLESvuwHkACY9?mode=gi_c
- Long COVID and ME/CFS Education Modules that BHC created with Emerge Australia are available for free here:
  - https://emerge.org.au/lea-ea-bhc/
- For those who are starting physical therapy, here are some important resources:
  - https://batemanhornecenter.org/providers/mecfs/diagnosing-managing/rehab-professionals/
- Disabled and Chronic Illness Dating Site
  - https://info.dateabilityapp.com/
- This is helpful to begin to get one's head around radical acceptance:
  - https://youtu.be/81sCMCC5SOI?si=oju_p_ScqGZ9Arb8

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.