

Support Group Recap: Grief – Making Peace with the Unknowns of Chronic Illness

August 13, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
 - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is recruiting for two Long Covid studies.
 - <https://batemanhornecenter.org/research/>
- Read the latest newsletter edition [here](#).

The following resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance nor endorsement.

Licensed clinical social worker, Timothy Weymann led this session. Facing and addressing the unknown is part of the human experience, but chronic illness tends to magnify unknowns.

Timothy provided the following list of questions to guide the conversation:

1. What has your experience been like facing the inevitable unknowns of chronic illness?
2. What are the barriers that interfere with your sense of peace amidst the unknown?
3. What helps you face the unknowns of chronic illness?
4. If you have been on your illness journey for a while, what advice would you give an earlier/younger version of yourself who began to face the unknowns of chronic illness?

Timothy's shared wisdom:

- When he began facing his own illness the lack of ability to predict anything was one of the hardest things.
- When symptoms are higher, accept them where they are. Tomorrow will be a different day.
- Does anyone ever really know what's ahead, chronically ill or not?

- Living creatively with limitations can help manifest your self-identity. Is there a more expansive definition that we can come up with about who we are that respects our limits and what we are going through? We are all in that journey of discovery.
- Dealing with material needs is difficult with chronic illness and does expose the limitations of some systems.
- You have survived to this point. You have found a way to get through and survive. Chronic illness survivors are some of the strongest people there are.
- It can be helpful to focus on what you have accomplished so far and recognizing your strength for what you have been through.
- Help is out there, keep hope alive.
- Boldly express your wants and needs, and boldly stand up to it when you are faced with prejudice.
- I can trust myself to handle things as they come, even with my limitations.

Participant Comments:

- Listen to your body and do what feels right for you. Doctors don't always know.
- "I would say to my younger self, 'Doctors can't necessarily fix you. Chasing a fix takes up all your energy. Don't fixate on recovery but focus on your present and learn to manage where you are at. Focus on today, right now. There is a difference between healing and curing.'"
- Reducing or releasing expectations helps manage the unknown. Being OK with inconsistency helps manage the really hard things.
- "The biggest challenge is learning to live in the moment. I was raised to think a lot about and plan for the future such as the wedding, the career, bigger house, faster car. This is an overwhelming mindset when so much is unknown. Dropping out of the rat race is hard, but learning to live with less is the path to take. Eventually you may be forced to, which has a different impact than choosing to slow down."

- “I am gradually getting used to pacing. When I know that I have to rest, I get frustrated because I can’t do anything without cognitive effort. Not having something to do interrupts my sense of peace.”
- Be okay with your emotions. It’s ok to be sad. You don’t have to be a happy sick person. You can be grateful for treatment etc. and sad that you need it at the same time. Being proactive about protecting your peace can help carry you through the hard parts.
- “The feeling of grief and loss and frustrations that come from being forced to stop working in a career that I loved abruptly was devastating. It affected my self-identity. A year later there is still grief, frustration and anger.”
- “Something that helps me accept and move forward with this illness is to focus on what I still have. Gratitude in general is helpful. Crashes do make it hard to be grateful, but there’s always something. I am still able to be an artist. Maybe I can’t do as much as before, but I am still able to call myself an artist. There are partial losses too. I also feel like I’m letting people down. Balancing all of these things is so difficult.”
- “My biggest stress is financial stability. I push hard to survive and that’s terrible for the disease. Looking for tools and foundational pieces is hard, and reaching into the patriarchal system makes me feel like I just go splat on the windshield. The worry of financial instability ripples to so much. The system is not set up for people who really need it, and it’s so broken. People who need real help need a menu and some help to select from what is available. Prejudice against people who have Medicaid is real, and shocking.”
- “I have come to be grateful that I don’t have to go to work. I am able to be creative. It doesn’t solve financial limits or a fixed income, but being creative does help me feel better. Also, letting feelings roll through and happen is better than trying to fight them. The wave does end.”
- “The isolation is the hardest part. All my eggs are in one basket as far as connecting with people. It isn’t fair to my wife or healthy for me. Leaving the workplace resulted in a big loss of community. Being fearful of a crash is further limiting. It’s easy to be afraid of doing too much and then more or less doing nothing. It’s a vicious cycle.”
- “I put all of my art and craft things away for 32 years and had given most of it away. But participating in something interesting to me (beadwork) did reignite the interest in

doing things again. Just having hands on the things I like to do, even without producing a finished product is beneficial. Do what you are able no matter how small.”

- Thank you for being real and open about the realities of chronic illness. The socioeconomic difficulties, financial, judgement from people in power, including doctors, and difficulty accessing resources such as caregivers is a long time battle that chronic illness and disabled patients don't have the bandwidth to fight on their own. You must have faith, whether it's religious, in other people, or in yourself that if you keep going you will find the bridge that you need.
- “In case it brings some hope to everyone for progress, Senator Bernie Sanders, along with several co-sponsors introduced the Long Covid Moonshot Bill, which includes other infection-associated chronic conditions (IACCs), including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). <https://solvecfs.org/long-covid-research-moonshot-act-of-2024-introduced/>”
- Reach out to senators to encourage them to support the bill.
- Being in the moment is helpful.
- “Critical care physician of many years, and now as an ME/CFS patient I cannot even help myself. Avoid mentors who have recovered and now charge for support and retraining services. I am looking for ways to support that will be less costly. Surrendering and letting go.”

Quotes Shared

- “Should I cry that it's over, or be glad that it's so hard to let go?”

Resources Shared

- The "211 national hotline" is a free, confidential phone number that connects people to local community services like housing assistance, food banks, healthcare, and crisis support, essentially acting as a directory to access help in your area; you can dial "211" to reach it.
- Free pacing tutorial
 - <https://cfselfhelp.org/pacing-tutoria>

General Resources

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 (meets on Zoom twice a week)
 - <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](#).