

Support Group Recap

What Does it Mean to be “Chronically Ill?”

June 7, 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. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.
- Latest newsletter: <https://batemanhornecenter.org/wp-content/uploads/2024/03/Winter-2024-newsletter.pdf>
- Please note the support group date changes for July:
 - Tuesday, July 16, at 1 pm, MT
 - Tuesday, July 30, at 1 pm, MT

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. He introduced the discussion by asking the group what it means to be chronically ill in the various settings of our lives such as work, school, family, romantic relationships, spiritual, or religious.

Timothy’s shared wisdom:

- There can be a feeling of aloneness and separation but remember that you could never not belong. We belong to the earth and to each other.
- “But you look good!” Is a common response we can get from friends, family, and the community. People don’t always know how to be with things that are difficult, so they switch the conversation because it’s uncomfortable for them. Unfortunately, a lot of us experience that as invalidating and dismissive which on a level it is but Timothy encouraged everyone to do their best to filter that out as not being about their illness but other people’s capacity in the moment to be with something that is difficult.
- We have to deal with both our own denial and other people’s denial as well. We often go to the mindset of denial when we have an unbearable story about our experience. If

we can keep building capacity to face losses and differentiate what is a permanent loss vs a temporary loss, then that can help us with the acceptance piece.

- Mindfulness teaches us that we are not what we do or are capable of. Rather, we are our awareness, and we can carry that with us through every experience of life, whether it is an internal or an external aspect.
- Timothy invited the participants to consider what they “do” as part of living with these illnesses such performing complex case management, healthcare advocacy, caretaking for oneself.
- Everyone here is an expert on their own body.
- Timothy shared that at the beginning of his illness he wouldn’t go to activities because it was too emotionally painful but as he adapted, he could attend activities and be okay with not participating in some aspects of the event.
- Self-acceptance is key.
- We become minorities with chronic illness and just like any minority there is a need to explain to others what it’s like to those who don’t understand *yet*. Being able bodied is temporary for everybody.
- When people don’t have the relationship skills to be open and understanding we can mistakenly take that inside of us and feel bad about ourselves when in reality it is the other person’s problem by the way they are responding. We do have to walk the balance of explaining for understanding but are not obligated to explain, defend, or justify.
- In adapting to our illness we have to develop a different kind of hope. Does hope come from the idea that this illness is going to go completely away? Or does hope come from the idea that I’m going to keep learning to manage it better and still reclaim what I can, not in spite of the illness but with it.

Participant Responses to What it Means to be Chronically Ill

- Recurrent pain juggling the sick self vs. well self.
- Plan more, pace more.
 - Frustrating to have to think of life in such a minute way (plan, plan, plan).
- Feel so much slower and less productive.
- The unpredictability is beyond frustrating.

- Living a game of whack-a-mole because while addressing one symptom another one comes up out of nowhere.
- Budgeting time, constantly.
 - Budget in preemptive and recuperative rest.
 - Even with the best laid plans, can still crash.
 - Can still do many things, but it may take longer or must tackle in smaller ways.
 - “Care to slow down with me?”
- Hard to accept self.
- Your body is fighting so hard.
- Changes everything.
- Limits
 - See life in a limited way.
 - Guilt for not being as productive as you once were.
 - Feel like always letting people down.
 - Misunderstood
 - Even good days can result in a crash.
 - Living life in increments.
- Isolation & loss
 - Feels like you are watching yourself.
 - Sadness of missing out.
 - Feeling misunderstood.
 - Feel less a part of society.
 - Feels like we are on a different planet than other able-bodied people.
 - Isolation, loss, limitations, and perpetual grief/grieving.
 - Invisibility makes everything harder.
 - Feel like I am living a shell of a life.
 - Had to end friendships with people who couldn’t understand why she couldn’t do the same activities they did together before she became ill.
- The never-ending rollercoaster ride.
 - Constant uncertainty.
 - So much ambiguity.
 - Always changing baseline.
 - Trying to find a way to navigate the ebb and flows.
- Wake up each day waiting to not be ill.

- Fighting against hopelessness.
- “Your health is unreliable, not you.”
- Economic challenge
 - Increasing meds = increased cost.
 - Difficulty finding resources and supports.
- Opportunity to explore self in new ways.
 - Always learning more about myself.
 - Living and accepting the unpredictable.
 - Find different ways to “be” in the world.
 - Explore new/adaptive hobbies.
 - “Remake life and be happy.”
 - Starting over allows you to reimagine life, every moment of it!
- Spirituality/Religion
 - Really knowing that I’m a part of nature. Didn’t come to know that until I became chronically ill.
 - Struggle to be a part of religion because of the expectations for callings.
 - Experience frustration with being told by religious friends to have faith and that would lead to healing.
 - Allows space for more spiritual connection.
 - Constant need for mindfulness.
- Acceptance
 - Having compassion for my own body.
 - Reclaim relationship with your body.
 - This disease really forces you to love yourself and the abilities your body does have.
 - Allows you to live a new life.
 - Slows down time which gives space for new things.
 - Don’t take things for granted anymore; appreciate the small things.
 - I try to put my smile on every morning, not so that others feel better around me but a smile on my face brings a bit of sunshine into my life and lifts my spirit.
 - Decreasing resistance to reality saves energy too.
 - Good afternoon all, I read something this morning I think is worth sharing. Be

- thankful for today. So many did or do not have the chance to grow old or be here today. We all do..I am very thankful for that-
- Even with ME/CFS. The struggle is real but the alternative is worse.
- I have a right to be alive and to be myself and still express/enjoy life.
 - Attune more to your body and what's going on in your life.
 - Realized that she can still be happy.
 - Integrating illness as a part of our life can help with acceptance. Instead of seeing ME/CFS as something that attacks from the outside, seeing the illness as "this is just my life" has brought some peace.
 - Loving oneself.
- Experiencing misunderstanding or ignorance from others
 - Takes so much energy to explain.
 - Feels more isolating with the disbelief.
 - Painful when others won't accept or understand your limitations.
 - "You either die young or you will live with a disability and require support" and it's helped my loved ones accept that everyone needs assistance of different kinds and at different times.
 - Some denial/struggle to accept
 - Struggle to believe chronically ill.
 - Feels like a prison sentence.
 - Nothing is the way it was before.
 - But you look good!
 - My view is looks are only skin deep, real beauty comes from within. So when people tell me I look good I figure they've seen that and take it as a compliment.
 - Let your inner beauty shine through.
 - I take it as "the energy they get from me is positive right now and they like it" so it's reframed and doesn't sound like "compared to usually when you look like hell."
 - Explaining to others
 - Tell others that I have a disability rather than chronically ill in case they think I'm contagious.
 - Explain that their illness is similar to Long COVID because they got sick after having a virus.

Quotes Shared

- “Resting is not laziness, it’s medicine!” — Glenn Schweitzer
- “Sometimes you will be in control of your illness and other times you’ll sink into despair, and that’s OK! Freak out, forgive yourself, and try again tomorrow.” — Kelly Hemingway
- “Talking about our problems is our greatest addiction. Break the habit. Talk about your joys.” — Rita Schiano
- “Behind every chronic illness is just a person trying to find their way in the world. We want to find love and be loved and be happy just like you. We want to be successful and do something that matters. We’re just dealing with unwanted limitations in our hero’s journey.” — Glenn Schweitzer
- “You are strong when you know your weaknesses. You are beautiful when you appreciate your flaws. You are wise when you learn from your mistakes.” — Unknown
- “We must accept finite disappointment, but never lose infinite hope.” — Martin Luther King Jr.
- “No one is able bodied forever” -Timothy Weymann
- “The truth is we’re all a little bit broken. We must learn to love the broken pieces of ourselves—be gentle and empathetic with ourselves and others.” — Karen Salmansohn
- “It’s not selfish to love yourself, take care of yourself and to make your happiness a priority.” — Mandy Hale
- “Live to inspire and one day people will say, because of you, I didn’t give up” — Doe Zantamata
- “If opening your eyes, or getting out of bed, or holding a spoon, or combing your hair is the daunting Mount Everest you climb today, that is okay.” — Carmen Ambrosio
- “The measure of who we are is what we do with what we have.” — Vince Lombardi
- “I long to accomplish a noble task, but it is my chief duty to accomplish small tasks as if they were great and noble.” — Helen Keller
- “Our greatest weakness lies in giving up. The most certain way to succeed is always to just try one more time.” — Thomas Edison
- “Maybe life isn’t about avoiding the bruises. Maybe it’s about collecting the scars to prove that we showed up for it.” — Hannah Brencher

Resource Shared During the Session

- <https://www.goodreads.com/book/show/59867868-my-body-is-not-a-prayer-request>

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
 - <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](#).