

Support Group Recap – Self Compassion with Chronic Illness

August 20, 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/>
- Fall Newsletter
 - <https://bit.ly/4dFq79e>
- Donate to BHC to help keep these support groups free.
 - <https://batemanhornecenter.org/donate/pay-form/>

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 started the discussion by introducing Self Compassion. The three ingredients for self-compassion are:

1. Mindfulness (vs over identification)
2. Kindness to self (vs self judgement)
3. Common Humanity (vs self-isolation)

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

1. What does being self-compassionate as a chronically ill person look like to you?
2. In what ways does judging yourself interfere with your adjustment to illness?
How do your self-judgments manifest?
3. How do you practice self-kindness as you manage your symptoms?
4. What are ways, as a chronically ill person, that you are similar to non-ill people?
5. What helps you manage difficult emotions in response to aggravated symptoms and flare-ups?

6. What helps you be mindful and present in difficult times?

Timothy's shared wisdom:

- There are other people who understand, and you are not alone!
- Our bodies are both a narrative of and a monument to our survival!
- Improvement for a chronic illness survivor doesn't have to be physical. Mental, emotional, or spiritual improvement is still valid improvement!
- "I will not personalize other people's limitations...or my own."
- In response to questions or intrusions from others, firmly ask "Is this a question or a judgment?" and hold the boundary of self-advocacy.

Participant Comments

- Why are we so likely to feel shame, guilt, or embarrassment about our illness?
Self-compassion is easier to understand why these feelings exist.
 - Timothy shares: The reality is that we are wired to survive, and that if we are perceived as weak, we are more likely to be attacked. It is human nature to want control, which is hard to fight with little or no ability to control your own illness and how your body responds to the environment around you.
 - Those with chronic illnesses are often not believed by those around them that they are truly ill, even by family and friends.
 - We are culturally conditioned to tie our self-worth and value to our productivity in a "corporate culture" sense, and that if you aren't capable of hard work you don't deserve space.
- Letting go of "hustle culture" has gotten easier over time, but personal things are hard to let go of – like not being able to participate in activities that you value such as taking care of children or aging parents. (Timothy: This is clean suffering and being self-kind is important.)
- Feeling guilty about the need for ongoing financial assistance is difficult to manage. Learning to accept help is hard.
- "Acceptance whack-a-mole" – accepting one facet of a need or situation is one thing, but new ones pop up all the time, and complex illness requires complex acceptance.

- “Invisible illness” is so hard for others to understand, so being with others who share aspects of the experience helps to build the sense of common humanity and feeds self-compassion.
- Conditioning from childhood trauma and other adverse childhood experiences contributes to difficulty with self-compassion.
- “One of the things that works for me is to recognize that we are all so courageous to withstand all we have to cope with. Admire other people but admire yourself in the same way for all the things that you put up with.”
Forgive yourself of errors and share self-affirmations that you are good and worthy.
- There are a lot of difficult emotions and extending compassion to the self through hard emotions, like depression is hard. What helps when everything is flaring and I feel like such a burden?
 - Thank your caregivers and helpers profusely and show gratitude. It’s constructive and lets other people know you are aware of the help.
 - Be grateful for yourself!
- Remind yourself that if other people don’t want to deal with your illness it’s not about you, it’s about them!!
- Hope helps.
- Though toxic positivity is real and important to recognize, genuine positivity is so important. There are little things to be positive about, and positively reassuring yourself can be helpful and fortifying.
- “It’s all true at the same time” - grief and joy, anger and acceptance, frustration and contentment. Complex feelings can coexist.
- Being a recovering perfectionist and someone who is very work identified, feeling compelled to do something interferes with feeling worthy. When encountering the difficult emotions around complex illness, giving myself time to breathe, resisting the urge to flee or shy from the difficult things, and diverting to something else that I can do to satisfy the urge to do something helps. Finding alternatives instead of a yes/no black and white helps to increase sense of fulfillment and productivity.
- The body is healing all the time, and illness can reveal opportunities to make changes and alter perspectives.

- Our brains are good at gaslighting us “You aren’t sick, you’re just lazy.” Don’t believe it.
- Advocating for yourself is a form of self-compassion.

Quotes Shared

- “You must have chaos within you to give birth to a dancing star.”
-Friedrich Nietzsche

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/invisiblyyouthgroup>
- 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](#).