

Support Group Recap: Self-Compassion Amidst Chronic Illness

February 11, 2025

Announcements

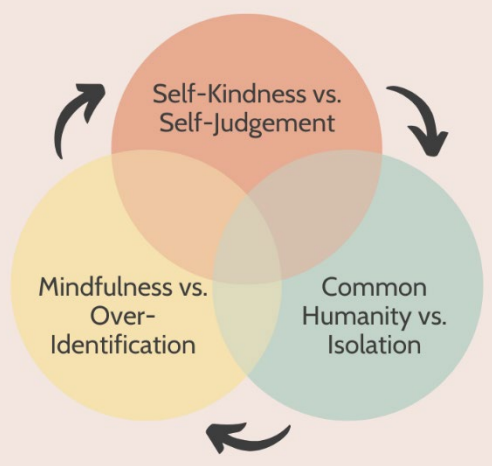
- Subscribe for Zoom recaps, updates, and invitations for future events.
 - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is recruiting for clinical trials. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.

The following resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance or endorsement.

Timothy introduced the topic by giving an overview of self-compassion. Self-compassion is composed of three domains.

- **Self-kindness versus self-judgement.** Do you greet yourself in the face of challenges with a sense of understanding, patience, gentleness, affirmation, validation? Or are you harsh, critical, self-condemning? Some folks can slip into being hard on themselves about their illness.
- **Common humanity versus isolation.** With illness, are you able to maintain an awareness that you are connected to others and that you aren't uniquely different in a negative way? We can isolate ourselves mentally by judging ourselves for illness or disability.
- **Are we mindful, or do we over-identify?** Are we able to observe our emotions and thoughts? Or do we get taken hostage by them? They can take control which often happens in chronic illness because the psychosocial stressors are high, and we can get overwhelmed with strong emotional responses. You know you have self-compassion if you have cultivated those alternative approaches.

Key Components to Practicing Self-Compassion in Chronic Illness



Timothy Weymann, February 11 Support Group

Self-Kindness vs. Self-Judgement

Are you kind and patient with yourself when facing challenges, or do you tend to be harsh and self-critical?

Self-compassion invites you to embrace gentleness and affirmation, even in difficult times.



Timothy Weymann, February 11 Support Group

Common Humanity vs. Isolation

Do you remember that you're not alone in your struggles? Illness can make us feel isolated, but we are all connected through shared experiences.



Timothy Weymann, February 11 Support Group

Mindfulness vs. Over-Identification

Are you able to observe your emotions and thoughts without letting them control you? In times of stress, it's easy to become overwhelmed, but mindfulness helps us stay grounded.



Timothy Weymann, February 11 Support Group

Support Group Discussion Questions

1. What is your level of self-kindness like when you are in flare-ups?
2. What have you noticed happens to your emotional state and your external world when you judge yourself for being sick?
3. What are effective ways you deal with both social/literal and psychological isolation (i.e., psychological isolation occurs as ill people when we see ourselves as unique in a negative way)?
4. How do you keep yourself from becoming emotionally overwhelmed as you face challenges associated with your illness?
5. How do you talk to and treat yourself when you are being self-compassionate in the face of illness, limits and loss?

Timothy's Shared Wisdom

- It's important to allow the waves of feelings and then rest rather than quit when you are overwhelmed.
- We can ask ourselves the following questions:
 - Can I make room for it to take time?
 - Can I make room for me to be just as I am?
- In a general sense, as human beings, we get addicted to self-blame as a counterfeit means of power and control. We can be aware in our own lives that when we go towards self-blame, we are usually feeling vulnerable and we want to pinpoint a way we would have power and control.
- Remember that we can accept ourselves as we are. We don't have to judge what we are going through.
- In some ways people helping us is a gift to them because it is important for people to learn to help and look outside themselves.

Participant Verbal Comments

- Participant shared the experience of having disappointments and overwhelm yesterday causing her to almost give up on a project she is working on. But today she was able to acknowledge that yesterday was difficult but that she can let go of the feelings and see them as passing through. This ability helped her greet today with fresh eyes and a fresh heart.
- Participant shared that she has found the meditations specific to self-compassion and loving kindness on the Insight Timer app to be helpful. She also enjoys the connection of live sessions because it allows for written comments and responses.
- Participant shared the following self-love practices that he does from his bed daily:
 - He pulls his knees up to his mouth and kisses them saying, “I love you so much.”
 - He imagines his dad who is no longer living say, “I’m so proud of you, son. I know this isn’t easy. I know this is so hard, but I’m so proud of what you are doing. You are doing such a good job.”
- Participant shared that when she is struggling to do something like having technical problems with her phone she tries to relax and think about what she would need as a child and tries to provide that for herself. Such as a hug, she will snuggle up with blankets and a pillow and try to make herself feel as loved as possible.
- Participant thanked the group for listening and helping him feel seen.
- Participant shared that she does breathe work to help her calm down when she gets overwhelmed with certain topics and challenges. She also allows herself to swear whenever she wants because otherwise the frustration stays inside of her. She also recognizes when she needs to vent and asks her mom to simply listen to her for a few minutes while she vents without expectation of having solutions offered to her.
- Participant shared that when she feels activated or in a flare, she can automatically pull on the knowledge learned from mindful meditations. She also tries identifying what is soothing for her such as touch so she will hold her own hand or hold a warm cup of tea to help center her. Being aware of her own needs

and values in a mindfulness practice has helped to contextualize some of the difficulties she faces because of her body or external environment. When feeling left out she allows the tears to cleanse her and realizes that time or space wasn't right for her. She gives herself the validation needed to continue to seek or find comfort in community.

- Participant shared that she has been a pleaser but that she has learned that if she is in a group where she doesn't feel comfortable, she is able to leave and realize that nothing is wrong with her. It just wasn't a good fit.
- Participant shared that she speaks to herself in the third person with reassuring phrases like:
 - "You are doing your best."
 - "I'm proud of you for resting."
 - "Your self-worth is not based on how productive you are."
- Participant shared that she is enjoying a meditation by Tara Brach called Rain.
- Participant shared that trying to process emotions 24/7 is exhausting so she works to strike a balance between processing and focusing on self-compassion.
- Participant shared that she focuses on low stimulation activities to counteract the internal dialogue of self-blame. She enjoys reading Japanese comics and has found an online platform that includes messaging capabilities enabling her to connect with others who have a similar interest.
- Participant shared her tips for having ME/CFS for over 35 years:
 - Stop blaming yourself and blame the illness instead.
 - Once you have a diagnosis, give in but never give up. Keep up with the research and medical providers.
 - If you wouldn't say it to the person, you love the most, don't say it to yourself.
- Participant shared that she practices self-compassion by giving herself permission to be ill because it wasn't an option in her childhood. She also finds it helpful to put her hand over her heart in a way that gives a similar sensation as a hug. It can be calming and a reminder that she is soothed and loved.

Participant Comments from the Chat

- "Happier and Calm apps are also helpful (meditation/mindfulness)"

- “I also find the insight app useful.”
- “The newest app I'm using is the Finch app which is good for me. ❤️”
- “Anger is such a big part of this. It’s important to be okay with this emotion, in ourselves and in others.”
- “Hal's tips remind me of our body's sensory and touch needs. I've started using a dry brush over my entire body before bathing. It's said to exfoliate but also benefits gentle nerve stimulation and lymph fluid as you move the brush upwards and toward the heart. It feels great to me but might not be for everyone if you're more sensitive.”
- “I work to stop and ask myself, ‘If a dear friend was struggling with this issue/concern how would I respond to them’ helps me move into compassion.”
- “I love Korean Dramas - so easy on the mind!”
- “When facing illness, self-compassion can be expressed through quotes like:
 - ‘May I be kind to myself in this moment.’
 - ‘May I give myself the compassion I need.’
 - ‘This is a moment of suffering, suffering is part of life,’
 - ‘You are not your illness,’
 - ‘Embrace your pain with kindness, not criticism.’
- “Self-compassion is not about being soft on yourself, it's about being kind to yourself, especially when you need it most.” - Kristin Neff
- “Every day may not be good, but there's something good in every day. Focus on the good, no matter how small.” Alice Morse Earle
- “We must accept finite disappointment but never lose infinite hope.” Martin Luther King Jr.
- “Can I order a replacement body, please? This one is constantly malfunctioning.” Unknown
- “I'm loving 2 books right now by) 1 by Miranda Hart (comedian) and 2) 1 by Meghan O'Rourke”

Chat responses specific to a verbal question about managing headaches:

- “Ice on the back of neck - soak the feet in hot water and turn on the block for blue screen on phone. It all works for me.....hope it helps ❤️”
- “I dunked my face in ice water yesterday for a migraine I couldn’t get rid of. It helped.”

- “Absolutely with headaches and migraines - my best way is PACE - cognitive/physical/emotional”
- “Migraines are rough. I get periods of days with migraine. I use a Headache Hat (from the freezer) & Weather X earplugs for barometric pressure changes, stay well hydrated, regular eating & sleep habits help. Check my diet to see if I have had any trigger foods for me - alcohol, caffeine, gluten. I usually dose with CBD oil, GABA & L- theanine which all seem to help at the beginning of the migraine. Sleep is often the biggest help getting through the migraine. So sorry you are dealing with this! ❤️”
- “I take Tylenol and use heat on my neck when I get migraine like that”
- “Excedrin, cold pack on head, ear plugs, eye drops, nose saline, dark room and try to sleep.”
- “I have a medication that works well if I take it ASAP when I get one - Rizatriptan - but I rarely get them since I started meditating and doing full-body scans for tension.”
- “Headache hats have saved me. I wear one all the time.”
- “Craniosacral therapy? multi-antihistamine approach?”
- “Cold bottle” at night under the nape of my neck to break the cycle”
- “Tizanidine/Zanaflex (muscle relaxer) helps me the most with migraines. For really bad ones, Fioricet.”
- “Turn off the lights, lay flat, take deep breaths, have a sip of caffeine soda, tea or coffee, and take 2 ibuprofen it helps my bad headaches. For migraines I take Sumatriptan.”
- “I’ve battled post-Malaria ME/CFS since 2012, with new onset headache that spiraled into chronic migraine in 2018... Migrelief NOW and 1000 IUs of Vitamin E daily have helped reduced Sumatriptan use.”
- “My friend who has had lifelong migraines has had awesome success with Botox.”
- “Migraines are rough. I get periods of days with migraine. I use a Headache Hat (from the freezer) & Weather X earplugs for barometric pressure changes, stay well hydrated, regular eating & sleep habits help. Check my diet to see if I had any of trigger foods for me - alcohol, caffeine, gluten. I usually dose with CBD oil, GABA & L- theanine which all seem to help at the beginning of the migraine.

Sleep is often the biggest help getting through the migraine. SO sorry you are dealing with this! ❤️”

- “I had ‘migraines’ for four years and found out had structural ME(CCI/AAI). I had a Craniocervical fusion, and the ‘migraines’ were gone. Ice was my friend and massage.”
- “Sumatriptan is my migraine abortive. Magnesium glycinate, electrolyte water, and saw palmetto (has a hormonal impact) help minimize migraine days for me.”
- “For migraines I take a zolmitriptan orodispersible tablet that I put under my tongue. It gets into the bloodstream faster than a tablet that you can swallow.”
- “I get migraines and what I call an ME headache. For the ME headache it is a sign I need to go straight to bed and rest. No medicine will touch it.”
- “For migraines I take a monthly Emgality shot and Nurtec as needed.”
- “I have discovered that paracetamol (apologies that’s the UK name) gives me headaches after a few consecutive weeks. I’ve heard it’s a thing with analgesics in general. Sending you solidarity and support.”
- “I get migraines too. Mine are not triggered by stress though. I see a neurologist and receive Botox injections in the office every three months.”
- “There are plenty of new meds for migraine these days, you might find some help there.”
- “I practice mindfulness meditation and some simple breath work, vagus nerve breathing is a fast and easy break for your body.”
- “Seek out a neurologist that specializes in migraine. My experience was decades ago, so no imaging or anything probably checked now, but spot on nonetheless, for a good experience and helpful outcome (beta blocker preventatively for about 18 months helped me for years after).”
- “Finding your triggers, which can range from foods (so also preservatives, food colors, etc.), cyclical/hormonal, air pressure/weather and more, might be combining for you with the neuroimmune influence of ME/LC, etc.”
- “I know it doesn’t work for all who try it, but in later years, I found a lot of relief using Cefaly, a medical device with an electrode you can use to treat a migraine, as well as prophylactically to help ‘retrain’ the reactions causing your migraines now to reduce (again, if applicable in your own case, like all else depends on the person).”

- “Later generation triptan meds can help interrupt migraines, stop them quickly, if available to you, might be another suggestion the neurologist suggests.”

Resources Specific to this Session

- Insight Timer <https://insig.ht/k94MsqddqUOb>
- <https://self-compassion.org/>
- <https://www.mindful.org/tara-brach-rain-mindfulness-practice/>
- *FIERCE Self-Compassion*, by Kristen Neff Ph.D.
- *How To Be Sick*, Toni Berhardt
- Dr. Yellman’s lecture on headaches: <https://youtu.be/gnFkBbC90Ws>

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](#).