

Support Group: Moving From Humiliation and Shame to Humility and Pride

August 19, 2025

Announcements

- Sign-up for BHC email to receive the recap:
 - <https://bit.ly/3rnvhjq>
- Clinical Care Guide:
 - <https://batemanhornecenter.org/clinical-care-guide/>
- Support BHC's One Guide. One Goal \$5 campaign:
 - https://givebutter.com/OneGuide_OneGoal

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

Timothy Weymann, LCSW started the conversation by sharing the importance and relation to self-construct. Exploring how we can move past humility and shame and become humble and more prideful through our illness.

Discussion Questions

1. How do you differentiate between humiliation and humility and how have these manifested in your chronic illness journey?
2. How does shame come up for you in relation to being chronically ill/having a disability?
3. What are you proud of about yourself in the context of facing chronic illness/disability?
4. What are the ways you have mistakenly/inadvertently reinforced your own sense of shame as a chronic illness survivor?

Timothy's Shared Wisdom

- If we are not intentional, we can internalize other people's ignorance. It is important to critically examine our expectations of ourselves and make sure we are living up to our own expectations and not somebody else's.
- It is important for us to keep the mindset of equality. When we let it seep into our heads that we are not equal we become more vulnerable to someone's ignorance getting into our head and heart.
- In the face of difficulty, it is easy for us to blame ourselves. Part of healing with chronic illness and adapting to it is to be mindful of our stories of blame and critically evaluate them.
- An antidote to shame is acceptance.

Verbal Comments

- Participant shared that they recently felt shame when their needs weren't being met in a support group they co-founded. They tried developing ways to make it structured and slowed down, but they were labeled too difficult. They also expressed that shame is experienced and felt through the healthcare system.
- Participant expressed feelings of shame when they are in a social setting. While their oldest friends understand everything, they live out of state and the friends they have in their current city have only known them sick and don't understand. They also expressed carrying a lot of shame from their early diagnosis and a big loss of self.
- Participant shared that they regard meeting new people as a job interview where they are not letting the person judge them but rather judging if that other person can be in their circle.
- Participant shared that for them humility feels really good. When they are able to say no and know their limits it feels good. They expressed that they feel humiliation when their family tries to grill them or give them health advice and that can be very hard.
- Participant shared that they are very proud of themselves for living with the pain and surviving this long. They focus on putting themselves first and learning their limits. Participant mentioned getting a sunflower invisible disability lanyard for the airport on an upcoming trip although it will be hard for them to admit they need that.

- Participant shared that since they have been sick for so long a lot of their shame issues are internal. It is about themselves and regrets for how they manage pacing. They internalize people's stories about pacing and feel that they need to improve. They also started using a wheelchair and it has aided them in leaving the house.
- Participant shared that when they go into a crash their first thought is that they overdid it and it's their fault. Then they fall into the cycle of shame. But they try to think of the flipside of that and how proud they are at how much they have been able to accept.
- Participant shared that since they got sick their whole identity has changed. They used to be very active and that was who they were. They also expressed feeling like they avoid social situations because they are so difficult and they feel like they need control in case they need to bail. Because of this they avoid social things and isolate which leads to a lot of self-blame. They feel as though the name chronic fatigue syndrome brings a lot of shame and that no one understanding the illness feels very shameful for them. They expressed feeling very isolated.
- Participant shared that a lot of the shame that they feel is from not being the person they used to be. They feel shame when they try to meet those same expectations and having to adjust causes them guilt.
- Participant shared that they have done a lot of medical testing but the results were negative, to finally be diagnosed with ME/CFS, they felt disappointed by the diagnosis and felt that it didn't encompass all that they were feeling.
- Participant shared that she learned shame as meaning "I'm a bad person" and how that is a heavy burden to carry around while being sick. They shared at the beginning of their illness they apologized a lot, and they have since worked through that a lot to learn they haven't done anything wrong.

Chat Comments

- "And mental health issues are physical too—they happen in our physical brain and impact our bodies too. We deserve compassion for ourselves there too, even though I know it's much easier said than done"
- "For the participant who asked about disability doctors' recommendation's before we got off. The below link may be helpful to you, UW rehab clinic put

together a SSDI guide for their patients in WA. Great step by step info for anyone needing:

- https://bpb-us-e1.wpmucdn.com/sites.uw.edu/dist/0/27887/files/2024/10/UWMLCC-Patient-Guide-to-SSDI_v1.pdf
- “For fun... My favorite Chronic Illness Gaslighting Bingo card:
 - <https://www.tumblr.com/mythopoetic-mixtape/787469251677192192?source=share>”
- “Hey, loves, speaking of wheelchairs and resources, this beautiful young man with ME is starting a charity to provide useful items to ME/CFS patients in the United States: black-out sleep masks, noise-cancelling headphones, grocery delivery subscriptions, shower chairs, heart rate monitors, lower-stimulation gaming devices, etc. <https://www.giftsforme.org/> Just discovered this today! I hope it’s okay to share. I think this is a wonderfully helpful, encouraging new resource. Everyone, spread the word!!”
- “This group is a soft space for us to land when the rest of the world is kicking us while we’re down. I’m so glad we keep showing up for each other.”
- “How to get on is a great resource <https://howtogeton.wordpress.com/>. The author was a friend of mine IRL. She taught me so much. It took me 20 months and 2 denials to get on SSDI and eventually had to get a lawyer. I followed the advice to get letters of support from doctors but this seemed to annoy the SSA folks and my lawyers and possibly made me seem more capable or powerful than I am? In the end they seemed most concerned with my "mental health" issues. I was in therapy and for whatever reason the lawyer thought the most compelling evidence were the notes my therapist took (not the letter she wrote in support) and they also got 3 letters of support from people in my life (roommate, daughter, old boss) that confirmed all I was saying. It seemed to mean more than my POTS tilt table or the 1200 pages of medical evidence that was presented. So, that is my 2 cents. And also answer questions in regards to your worst days, even if you have some good days. I hate to say it but the bad days seem to always come up again.”
- “For the person looking for a disability doctor consider consulting with disability lawyers as they may share doctors they work with who are very good at

documenting to support your case. You can get referrals to lawyers from your local bar association and most will offer a 30 minute consultation for free.”

- “Tracking my biometrics using apps on my iPhone and my smart watch has helped me a LOT in medical appointments because I can show graphs to medical professionals, and they get it then. It stops the gaslighting in its tracks.”
- “I’ve found getting food directly from farmers in CSAs (community supported agriculture) is cheaper. And I’ve been creative with how to get the food to me given my limitations”
- “I have decided to not say guilt but replace with grief.”
- “Learning about internalized ableism has helped me understand why I feel such shame and break the spell of other people’s expectations. I can love my family/friends (who don’t understand) and I know it’s not my role to educate, convince, beg or plead for support they can’t give. I know there are other places (like here) where I can get support.”

Tiny Triumphs

- “I was able to visit my family for a week. 9-hour drive, so it was kind of a big deal.”
- “I spent time with my 2-yr old granddaughter and survived.”
- “I was able to make my DSHS appointment. Drinking less coffee and more water.”
- “Ran a 2-hour Zoom call on Saturday while managing my spoons.
- “Made a phone call today and was ok.”
- “I had brunch on Saturday with a friend (I’m crashing now, but it was worth it)!”
- “Adding more water and sodium is really helping me.”
- “I made it to a relative’s 90th birthday party last month.”

Resources

[Clinical Care Guide](#)

[ME/CFS Crash Survival Guide](#)

[Pacing Education Modules](#)

[Life with a Low Battery: Living with ME/CFS](#)

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](#)

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 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/>
- 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 close 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](#).