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

September 09, 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 how today's session addresses the recurrent topic of the journey of those who are chronically ill.

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 disability?

3. What are you proud of 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

- Pride can come from us attuning to ourselves and engaging in productive rest. These are both very important.

- It is also important in life, even beyond chronic illness, to recognize our boundary of power and work within our area of power and let go of the rest.
- We can remind ourselves to be intentional and critically evaluate the stories of blame that come up in our minds in response to our illnesses and stressors.
- Humility is a virtue, and adopting it as such is part of recognizing our own vulnerability and accepting it, and not allowing pride to interfere with getting the connection we want and need.
- If we don't challenge our own internalized ableism (false negative judgments about being sick or disabled), we can reinforce our own ignorance about the illnesses we face and this can interfere with adapting our lives to them, and thus make our lives as people with illness inadvertently harder than they need to be.
- In a general sense, one way people can address shame for themselves is behaviorally through exposure. Getting vocal and not hiding can make someone desensitized to unhelpful shame because each time we do it we reaffirm to ourselves that we are worth being seen and heard; we can also learn through this process that there are other people we will connect with and who will accept us just as we are. We also indirectly model the power of authenticity to others as well.
- Humans will project their own issues or problems onto others; this can express itself onto us by the way some may make odd or hurtful comments to us about our illnesses and/or disabilities. Recognizing these appropriately as projections can help us rightfully push it back out as the responsibility of the speaker, and help us not unhelpfully internalize them as accurate comments or things we need to take on and manage. This can be a powerful internal skill/tool to develop.

Verbal Comments

- Participant shared that people saying attitude plays a big role in chronic illness causes them a lot of shame. This shame can cause them to push past their energy limits.
- Participant shared that they have been resting a lot. They accidentally pushed themselves and relapsed which was discouraging but they were proud of themselves for resting more. As they are resting, they are taking care of their mental health because it is physical stuff that they have been doing too much of.

They expressed that they have a lot of recovery to make around the illness because of all the guilt, loss, shame, disappointment, and grief that come with it.

- Participant shared that letting go of the shame from getting their diagnoses has been hard because it also meant letting go of an illusion of control. Acknowledging that this is something they don't have control over and that there are steps but there is nothing to be ashamed about.
- Participant expressed shame around feeling like there is so little they can do and feeling like everything just happens to them. They also feel ashamed that they take so many medications and shame around not being able to be in a relationship.
- Participant shared that their shame comes up when other people perceive their illness and they take that on. They also take on the stress of how it affects the people around them and their own grief. They shared that they recently learned that they don't have the energy to hold onto other people's grief about their situation and the only energy they have is with themselves. To them humility is accepting people's help and letting their pride go.
- Participant shared that they have found the book *How to be Sick,* by Tony Bernhardt helpful. Using Buddhist philosophies in situations where they might feel resentment. They also framed receiving help as putting it into the perspective of if a friend was going through this would they help them and give them grace. Vulnerability is the greatest courage because it allows us to let them in and strengthens our connections.
- Participant shared that they feel the most shame on the good days of their illness. When they have a good day, they feel like people perceive them as not that sick, which leaves them to feel ashamed or like they are faking it.
- Participant shared that they have found help in dialing the 9-8-8 number (crisis line) and while it might be hard, if you need it then it is worth it. They also shared that they found humiliation when getting a disabled placard and hearing people talk bad about them. They shared their personal motto of "If you don't put yourself first, you're just going to go backwards".
- Participant shared that they feel ashamed when they don't speak up and when they hide from things.
- Participant shared that when they go grocery shopping, they often times use a power wheelchair and grabber but still have to ask for help some days, they fear

that people think poorly of them because they could do it days before. They shared that they feel shame around having different limitations different days and that they are a “people pleaser.”

- Participant shared they are able to continue living and traveling in their RV full time by employing the pacing principles taught by "spoon theory."
- Participant shared that they haven’t figured everything out emotionally and feel like they still tend to blame themselves for ending up with chronic illness.

Chat Comments

- “My energy has been improving daily; able to cook, do chores, hobbies that I wasn’t able to do before.”
- “I tend to feel shame over not doing more. I am grateful that I can live with my parents and they support me financially, and I contribute by helping out around the house. They never make me feel shame, but sometimes struggle with others who are judgmental of me being an adult living at home with my parents and relying on them for financial support.”
- “Ooof letting go of the illusion of control.”
- “I’m trying to work up the nerve to be seen even here. I’m severe and totally bedridden. I was a spa/salon owner before ME. Had other serious conditions but was still able to work and run my business. I’m still rather vain so I’m struggling with being ashamed of how I look now and guilt of not working. My PCP retired and my the dr taking over is forcing me to come in for an in person visit so I’m scared, ashamed, and feel wronged. I’m scared I’ll get worse and I’m on the edge of very severe and it’s getting hard to eat.”
- “There is no shame in being depressed - or having the illness of depression.”
- “To me humility is acknowledging reality with honesty and acceptance vs humiliation trying to put blame and make someone feel bad and trying to shape the world to expectations.”
- “Hardest thing I had to learn is to let go of things I can't control. I now refuse to waist any of my spoons (energy) on anything negative or anything I can't control.”

- "I just realized that I hide my extra coach pillows and blanket when maintenance or contractors come by to service my unit due to my embarrassment. I love that all of you are modeling by keeping yours visible during our group session and I will challenge myself next time to not hide mine."
- "As a Nomad, I always think this is an option: https://cheaprvliving.com/"
- "I met a traveler from an antique land
  Who said: "Two vast and trunkless legs of stone
  Stand in the desert . . . Near them, on the sand,
  Half sunk, a shattered visage lies, whose frown,
  And wrinkled lip, and sneer of cold command,
  Tell that its sculptor well those passions read
  Which yet survive, stamped on these lifeless things,
  The hand that mocked them, and the heart that fed:
  And on the pedestal these words appear:
  'My name is Ozymandias, king of kings:
  Look on my works, ye Mighty, and despair!'
  Nothing beside remains. Round the decay
  Of that colossal wreck, boundless and bare
  The lone and level sands stretch far away."
- "I tell people, 'You only see me on good days.'"
- "https://howtogeton.wordpress.com/ has a section on how to find housing while disabled"

Tiny Triumphs

- "I came to this group."
- "I signed up for an online language course."
- "I'm thinking less about not being able to 'fix' this and just flow with it more."
- "Put myself first, something I find hard to do."
- "I washed my extremely long hair."
- "I read the book *How to Keep House While Drowning*. Thanks to those who recommended it. Super helpful."
- "I passed my professional coaching qualification this week & coached my first client."

- “I cut my bangs today!”
- “More like a HUGE TT. Only took 11 years, serval PCPs, and tons of Specialists but… I finally got diagnosed with ME a few weeks ago.”
- “I'm finally getting a few acupuncture sessions on the NHS.”
- “Pushed myself to travel to go to my aunt’s funeral. Suffered for it but happy I still chose to go to say goodbye to her and be with family.”
- “I made it to my doctor appt. and shared a printed copy of the new BHC Clinical Care Guide I had printed. He received it well and was going to take a read through it!! I'll be giving one to my Rheumatologist the end of the month.”

Resources

- https://www.whitneydafoe.com/mecfs/resources/

California Resources:

- Social Services General Aid Website
  - https://www.cdss.ca.gov/benefits-services
- CalFresh/ Food Stamps
  - https://www.cdss.ca.gov/calfresh
- California Life Line Program - Helps with getting low income phone plans
  - https://www.californialifeline.com/en
- California Medicaid
  - https://www.dhcs.ca.gov/Pages/myMedi-Cal.aspx
- California Benefits Application Page
  - https://benefitscal.com/
- CalWorks Assists Families in Need
  - https://www.cdss.ca.gov/calworks
- In Home Supportive Services
  - https://www.cdss.ca.gov/in-home-supportive-services
- California Housing and Homeless Programs
  - https://www.cdss.ca.gov/benefits-services/more-services/housing-programs
- LIHEAP - Energy Assistance Program
  - https://www.csd.ca.gov/pages/liheapprogram.aspx
- Prescription Assistance

  - https://www.rxresource.org/free-plans/california.html
- Medical Appointment Transportation
  - https://www.dhcs.ca.gov/services/medi-cal/Pages/Transportation.aspx
- California Independent Living Resource Center: https://calsilc.ca.gov/independent-locator/

New York Resources

- Health NY M.E Resources
  - https://www.health.ny.gov/diseases/conditions/me-cfs/
- Apply for the Supplemental Nutrition Assistance Program (SNAP) to help buy healthy food for you and your family when money is tight.
  - https://www.ny.gov/services/apply-snap
- Office of Addiction Services and Supports
  - https://oasas.ny.gov/
  - Call the 24/7 HOPEline at 1-877-8-HOPENY or Text HOPENY (467369).
- Reduced-Fare program
  - Reduced fares are available for riders who are 65 or older or riders who have qualifying disabilities.
  - https://www.mta.info/fares-tolls/subway-bus/reduced-fare
- Affordable Housing
  - https://portal.311.nyc.gov/article/?kanumber=KA-01966#:~:text=Visit%20the%20NYC%20Housing%20Connect….
  - https://hcr.ny.gov/find-affordable-housing
  - https://opwdd.ny.gov/providers/housing
  - https://otda.ny.gov/programs/emergency-rental-assistance/
  - https://camba.org/need-help/
- Child Care Financial Assistance
  - https://portal.311.nyc.gov/article/?kanumber=KA-03118
- Disability Parking Permit
  - https://dmv.ny.gov/more-info/parking-for-people-with-disabilities
- Access-A-Ride Services for those with Disabilities
  - https://www.mta.info/accessibility/access-a-ride/how-to-apply-or-recertify-for-access-a-ride
- Disability Benefits Claim

  - https://ww3.nysif.com/Home/Claimant/DBClaimant/FilingAClaim
- Unemployment Benefit Guidebook
  - https://dol.ny.gov/unemployment-insurance-claimant-handbook
- Shared Work Program
  - https://dol.ny.gov/shared-work-program-0
- Office of Mental Health
  - https://omh.ny.gov/omhweb/aboutomh/fieldoffices.html
- Health Insurance Saving Programs
  - https://aging.ny.gov/programs/medicare-and-health-insurance
- ACCESS NYC Programs and benefits; housing, income, food, etc
  - https://access.nyc.gov/
- Find Health Insurance
  - https://nystateofhealth.ny.gov/
- Health Related Needs Forms
  - https://www.health.ny.gov/forms/index.htm
- Health Insurance Financial Assistance
  - https://www.dfs.ny.gov/consumers/health_insurance/help_seriously_ill
- Patient Advocacy Help
  - https://oasas.ny.gov/treatment/rights-and-protections
- Insurance Obstacles Hotline
  - 888-614-5400
  - ombuds@oasas.ny.gov
  - https://champny.org/
- Energy Bill Financial Assistance
  - https://www.ny.gov/services/apply-heating-assistance-heap
  - https://www.ny.gov/services/apply-cooling-assistance
- Unemployment Assistance
  - https://www.ny.gov/services/get-unemployment-assistance
- Meal Service for Older Adults
  - https://aging.ny.gov/programs/food-and-meals
- Medicaid information for NYC Residents
  - https://portal.311.nyc.gov/article/?kanumber=KA-02861
- For the person in NYC having housing trouble. Try CAMBA
  - https://camba.org/need-help/

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

Chronic Illness Therapist Directory

- https://www.thechronicillnesstherapist.com/directory

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.