Support Group: When Things Get Tough – Managing Guilt and Shame with Chronic Illness

February 18, 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 Weymann, LCSW introduced the topic by defining guilt and shame.

- **Guilt** is an emotion we have that is a result of either hurting someone or going against our values.
- **Shame** is a sense of humiliation in a social context. There is usually a negative judgement or an anticipation of perceived or real rejection. Those rejection behaviors can be overt like someone pulling away, or they could be more subtle in terms of expressing prejudices about chronic illness or disability.

Support Group Discussion Questions

1. What do you understand to be the difference between guilt and empathy?

2. How does guilt manifest in you as you face your illness?

3. How does shame manifest in you as you face illness?

4. What helps you counter shame?

5. What do you miss out on when you mentally process the illness experience through mental filters that focus on guilt and shame?

Timothy's Shared Wisdom

- Experiencing shame can be clarifying. It gives us the opportunity to ask ourselves some questions.
    - What are the negative judgments attached to the shame that we hold? And how true are those judgments?
    - Whose fault is this?
    - Is there really a fault and blame in our illness?
- Sometimes, our shame is reinforced if we come from families or social groups that aren't as emotionally aware and who meet stressors with judgment.
- For shame to exist hiding usually must take place and that hiding can tend to reinforce the shame. Timothy wasn't suggesting that sharing details about illness is necessary but wanted the group to be aware of the concept.
- Many can easily confuse guilt with empathy. Guilt implies control and that we did or didn't do something. In some ways guilt can be a denial about our lack of full control in the face of illness and disability. There is an idea that if I can blame myself for this, there is some kind of control I can access. It can take a willingness to grieve in order to let go of guilt and recognize the boundary or where we do and don't have control. That can then turn to empathy for feeling how the illness is impacting us while realizing that it's not our fault.
- It's important to connect with like-minded people who are going through similar experiences, so we know that we aren't alone.
- In anticipation of rejection, we can sometimes reject ourselves first as a coping mechanism.
- We can spend a lot of time trying to convince other people about our illness, but they still reject the information. It can be helpful to depersonalize this by asking ourselves if they are really rejecting me or if they are actually rejecting reality. This can help reduce the painfulness of their rejection. It's also an opportunity to evaluate if our energy should be going toward someone else who will accept the reality of the situation.

- It's empowering to recognize the lines and the boundaries of what we are responsible for and what we are not responsible for. Mental health is about balanced thinking. If you focus so much on how your illness negatively affects your partner and other people in your life you may not be thinking about how it positively helps them and how other aspects of you that are positive are contributing to the relationship.
- If people are judging us and we're not challenging that, then it comes inside of us and anxiety and depression can develop. We can combat this by asserting ourselves as appropriate even when the people in our lives might not be willing to learn. We can always validate ourselves.
- Other people can tend to project their limitations onto us. Timothy counteracts this by not blaming himself for having an illness but rather realizing that the other person has a deficit in their relationship skills, communication, or empathy.

Participant Verbal Comment Themes

- Participants shared experiences of feeling shame about their illness when around their family or friends and the need to feel like they must hide how much they struggle.
- Participants shared feelings of guilt for what they can't do but believe they "should" be doing.
- Participants shared how they feel concerned about how others view them in public because they look and behave so differently due to their needs and limitations.
- Participants shared that they feel guilt and shame for requiring help from loved ones and for being "too much."
- Participants shared shame about having the term chronic fatigue syndrome in the name.

Participant Verbal Comments with Coping Lessons

- Participant shared that they spend time with other people who have disabilities and reading radical authors who imagine worlds for disabled people. This helps them to counter the shame that they feel.

- Participant shared that self-advocacy takes learning and listening to your own thoughts and countering them. It takes patience and being kind to yourself.

Participant Comments from the Chat

- "Hello, I was just checking my computer and Cort Johnson just posted a very interesting article on Health Rising. The article discusses a ME/CFS brain study. It is fascinating and very descriptive of my issues. https://www.healthrising.org/blog/2025/02/11/default-mode-network-chronic-fatigue-syndrome/"
- "This is another new fascinating study.. they determined hippocampus changes in long COVID / ME/CFS patients https://medicalxpress.com/news/2025-02-mri-uncovers-enlarged-hippocampus-covid.html"
- "Side note: I am really appreciating reading the book, The *Invisible Kingdom* by Meghan O'Rourke... in case it helps others.
- "It's easy to go to the 'less than' perspective when you actually can only do 'less than' your friends and family!"
- "The best thing I've learned here is using your spoons wisely. It took a very long time to figure out what to use them on and what to just let go. I'm so much better now using my spoons for things I really want to do. It opened my eyes to how much energy I was wasting on things that I was never going to be able to change, esp. in others."
- "One of my new life mantras is: reorienting my life around resilience and recovery."

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.