

Support Group Recap

Moving from Shame to Pride: Responding to Inappropriate Guilt

February 20, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
 - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is still recruiting for two Long Covid studies. 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 nor endorsement.

The support group session was led by Timothy Weymann, LCSW.

Timothy introduced the topic and defined the relevant terms.

- Shame is when we have a humiliating experience. It's a social experience and we are cognizant of how others are negatively judging.
- Guilt is different than shame in the sense that guilt is when we do something that hurts someone or goes against our values. This feeling is developed to alert us of that departure from our values.
- Inappropriate guilt denotes a level of responsibility that we did something wrong or hurt someone. We use the term inappropriate guilt when referring to people feeling guilty about their chronic illness. Individuals with chronic illness aren't doing anything wrong – we are just being. We are going through an experience that we don't have control over.

Participant Experiences of Shame/Inappropriate Guilt

- Self-doubt
- Doesn't want others to see how poorly they are doing.
- Others doubting why they can't do something.

- Feeling bad that you can't help others when they need it such as spouse or encountering someone in the community.
- Several expressed that feeling shame was the worst at the beginning of illness.
 - "As I came to accept my condition there were a few friends who came through that chaos. They are accepting that I have to lay down."
- Shame for not having pushed back earlier to find a diagnosis and find other community members to better advocate for the community.
- "It's frustrating to feel guilt when I know it's not something I did."
- Having support and having some answers helps heal the shame. "I've been reviewing all of the medical records to heal my shame and to accept that this is what I have."
- "Family members outside the home that don't want to understand and place shame on me until I work to get better."
- When people don't think you are doing enough.
- The ignorance of people, the health system, etc. and their unwillingness to learn the disease.
- People telling you to try things that you know won't work.
- People putting blame on you for not working harder to get better.
- Comments such as:
 - "Nobody in MY family has that."
 - "But you don't look sick"
 - "If you worked harder to..."
 - "Have you tried..."

Mobility Aids

- Feeling challenged to get over the change in public persona associated with using mobility aids.
- Stopped going into the community when they stopped working because they didn't want others to see them in a wheelchair and experience the lack of understanding.
- "I felt the same way yet once I had no choice I was so excited what I had it easier to still do more life. I actually now associate more with others in the ADA world and appreciate all the advances made by those before me I never realized were challenges."
- "I also bought a medical bracelet so people give me less judgement when I'm in public and I say I need a chair or anything."

- “I got my first wheelchair from my local Buy Nothing group and it really helped me ease into it.”

Pride

- “I am not ashamed of my disease anymore and I accept myself for who I am. I am not afraid to tell my family I have a homemaker. I get my grief and anger out through my art.”
- “I do have a sense of pride. I chose to start my video in bed with junk in the background because I was watching how many people were logging on and it choked me up to see the other people. I feel empathy for the other people in this situation. I don’t think I could have chosen a stronger physical, mental, emotional, spiritual package that I got put in before my illness and in my illness. But it has taken practice and a lot of grace and understanding of where my value stands. It matters that we treat ourselves with compassion. I feel like it’s really important to share that the beauty comes from within.”

Timothy’s Shared Wisdom

- He had a loved one respond with a sense of shock when he asked for help with a specific task. It registered with him as a level of shame. It’s a process where we start to doubt ourselves or question ourselves in our illness. He was able to work through the shame and responded with a statement like, “Yes, I do, or I wouldn’t have asked you.”
- We tend to personalize the illness experience. It’s helpful to take a step back and remember that health decline happens to almost everyone at some point in their lifetime. Being ill is not a statement about my worth or who I am. It just means that I’m going through a normal human experience.
- For shame to exist, hiding must exist as well. It’s okay to want privacy for your illness but I would encourage everybody to reflect where that comes from when you are being private. Is it because you need to protect yourself around someone who is aggressive or misunderstanding? Or are we reinforcing shame by trying to hide our disability or illness.
- The invisible part of our illness can be a barrier for us, and we have to compensate by being very good at communication. It takes a level of self-awareness on our part of knowing our needs and limits.
- We get afraid of upsetting others or the situation. But if people get upset, their problem is with reality, not with use because the reality is that you need the help.

- We get through shame and embarrassment by behaviorally challenging and saying there's nothing to be ashamed of here.
- If I share something about my illness it's good information for me if someone in my life isn't validating. It tells me there needs to be more boundaries with that person. People who are warmer and kinder will greet us with validation and empathy. That informs us that these are people we can consider having in our lives more because they are showing us that they have the capacity for a good relationship. The more information we have, the more power we have.
- You are worth telling the truth and standing up for yourself.
- Mobility aids
 - Getting over the change in our public persona will be harder the more we have judgement about how we are. If we can work on dropping those judgements it gets easier.
 - The Buddhist philosophy asserts that suffering is a big part of life and that attachment is part of our suffering. So, if I'm attached to projecting a certain persona that's going to create more suffering with my illness because I'm not that anymore. We can grieve and validate how painful that is while also accepting that none of us are who we used to be. But we can continue to go back to our core and continue to manifest it.
 - Speak to your physician if you need mobility aids because they can write a prescription for you.
- When we are ill the weak points of other people around us are more revealed to us. Some people confuse their illness with other people's relationship skill deficits. It's important to ask ourselves if this is really about my illness or the fact that my family member doesn't have a good level of empathy. If we're able to externalize then it can help guard against the depression and anxiety and the self-concept issues that can come with chronic illness.
- Ask oneself how helpful it is when I go to shame? How helpful is it when I self-blame?
- We can mislabel both empathy and anger as guilt.
- Rumi, "Don't turn away. Keep your gaze on the bandage place. That's where the light enters you."
- Can we move humiliation towards humility, and with that expansive openness to accept to appreciate beauty wherever we recognize it.

Resources Shared in this Session

- Book: How to Keep House While Drowning (“It was life-changing for me...it helped me get over a lot of the shame about my illness.”)
- [Mobility scooter. Foldable. \\$649 on amazon. Top Mate ES32](#)
- [Mobility device accessories](#)
- [Rollator](#)
- [Happiness.com](#)
- [Spoon Theory](#)
- [Comic that explains PEM](#)
- [A rollator for outdoor adventures](#)

General Resources

- [How to Be a Demanding Diplomat as a Severe ME/CFS Caregiver](#) (video)
- [ME/CFS Crash Survival Guide](#) (This guide is not only helpful for patients, but also in helping caregivers and providers understand what you are experiencing.)
- [Unrest](#) documentary
- [“Chronic Illness: What I Want You to Know”](#) communication card
- [BHC Patient Resources](#)
- Crisis Resources
 - Dial 988
 - [What Happens When You Call 988?](#) (Article)
 - Dial 911
 - [Crisis Text Line](#)
 - [Crisis resource page](#) (BHC)
- Support Groups
 - BHC Support Group 2nd and 3rd Tuesday at 1 pm MST
 - <https://batemanhornecenter.org/events/>
 - Surviving with ME
 - <https://www.facebook.com/groups/695317212152964>
 - ME/CFS Social Group
 - <https://www.facebook.com/groups/1202428297198122>
 - CFS/ME Friends

- <https://www.facebook.com/groups/CFSMEFRIENDS>
- 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>
- ME/CFS phone support group
 - Occurs on Saturday nights at 8pm, EST.
 - Call: 609-746-1155. Punch in: 915110#. Group is open to all.
- Massachusetts ME and FM Association Small Group Chats
 - <https://www.massmecfs.org/>
- #MEAction Living w/ME Support Group
 - <https://www.facebook.com/groups/211058135999671>
- Caregiver Support Group
 - <https://www.meaction.net/event/me-partner-caregivers-support-group/all/>
- Health Stories Collaborative Creative Meetups
 - <https://www.healthstorycollaborative.org/creativemeetups>