Bateman Horne Center
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Support Group Recap: Using Boundaries to Improve the Illness Experience

January 21, 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 explaining that boundaries are what differentiates me from you, and they are also the lines that we draw for safety. It can be literal boundaries such as the fence around your house or they can be interpersonal such as not talking about certain topics with certain people. Just like we have boundaries with others, we can have boundaries within ourselves such as pacing or where we focus our attention or the way we speak to ourselves. Another item to consider is which relationships do you have that could benefit from better boundaries.

The following questions provide a guide for the support group discussion.

1. What situations are you finding to be the most difficult in setting and maintaining boundaries when it comes to respecting your illness limits?

2. What relationships/social connections do you have that could benefit from better boundaries?

3. What's the hardest part about setting boundaries with others in the context of being chronically ill?

4. What are both the areas of strength and vulnerability you have in respecting your own boundaries (i.e., illness limits/disabilities)?

Timothy's Shared Wisdom

- An opportunity for emotional work could be letting go that some people will be annoyed and allowing them to be annoyed as is appropriate.
- Sometimes there are emotions that interfere with maintaining boundaries such as shame, humiliation, embarrassment and fear. There is something we fear that is preventing the line from being drawn or it becomes important for us to identify that fear and to critically reflect on it such as asking ourselves if it is a logical fear.
- A helpful framework based on traffic light colors—red, yellow, and green—can be to categorize people, topics, and activities.
    - **Red Light**: A clear "stop" or no-go.
    - **Yellow Light**: Proceed with caution.
    - **Green Light**: A full go-ahead.

  This system can help evaluate relationships, behaviors, or activities, especially in the context of personal boundaries and managing challenges like illness. Writing out red, yellow, and green light categories can provide clarity and assist in recognizing when we're in denial about problematic people or topics. The framework helps to visually organize and better manage boundaries and interactions.
- Empathy is an important relationship skill. If people have developed good relationship skills, they have the capacity and desire to listen. There needs to be boundaries around that such as we don't want to dump on people about how horrible this illness is but perhaps this is an opportunity for folks to prioritize finding people who are more empathic and open to listening as friends.
- Direct communication becomes even more important when we are ill because it helps to compensate for the changes and limitations. Being proactive and not waiting for the moment to communicate about something can be helpful.
- Some folks will confuse self-responsibility with selfishness, but they are not the same thing. However, pain can be self-absorbing so perhaps we can check in

with ourselves about how often we ask other people questions about what is going on in their life.

- We can tend to personalize other people's disappointment. A good reflection can be to question whether they are disappointed at ourselves or the reality of the situation.
- We often mislabel empathy as guilt. Empathy is the ability to understand and share the feelings of another. Guilt implies we have some amount of control or power. So, it is important to internally relabel the feeling from guilt to empathy for what the other person may be experiencing as a result of our illness. We can also go to guilt as a defense because we don't want to feel grief from the loss. Timothy encourages participants to experience the grief because it can help move away from the feelings of guilt.
- We can sometimes do something to compensate for missing an event such as asking if we can text or call on a lighter symptom day to see how the event went.
- We often face other people's limited relationship skills which then creates the need for a boundary. Direct communication can sometimes help address the issue such as saying, "Hey, I noticed that you have a hard time when I tell you no. Can you help me understand what this is about for you?" Asking that question won't be helpful with some people because they don't have the self-reflective capacity to answer. But it can be helpful with many people.
- Whenever you set boundaries there will be a detox period because the other person isn't used to that line (boundary). They can misinterpret it or personalize it into feelings of failure. You can recognize that in them and speak to it to help lower their defenses.

Participant Verbal Comments

- Participant has learned that putting her phone on silent at times is a boundary that helps her rest and pace.
- Participant shared that it is important to let yourself rest when you know you need it. Don't be embarrassed to speak up when you need help such as a wheelchair or cart that can help you to conserve energy and pace. As her son has gotten older and become an adult he understands the importance of allowing his mother to rest.

- Participant shared that she has had ME/CFS for 32 years and was able to experience remission twice, but she pushed herself back into a relapse. She used her experience to encourage others to rest and pace. *The Untethered Soul,* by Michael Singer helped her realize how to have personal boundaries and stop berating herself.
- Participant has been able to improve her ability to set boundaries with others by asking herself, "Are these people going to look after me when I become more ill from doing whatever I think they expect of me?"
- Participant shared that she finds relief from ruminating over responsibilities at night keeping her awake by imagining the walls of her bedroom as blocking out any other people. She reminds herself that she doesn't have to worry about anybody else or feel guilty.
- Participant expressed that we (chronic illness sufferers) should complement ourselves for the little things like rolling over or getting out of bed. It helps to provide positive, loving, and even humorous feedback while living with this very hard illness.
- Participant shared that she finds the author and YouTube personality Mel Robbins to have helpful information about maintaining boundaries. She especially appreciates Robbins's book titled, *The Let Them Theory.*

Participant Comments from the Chat

- "I have found using a smart watch to monitor my heart rate helps a lot with this."
- "I think brain fog in this context is the hardest because I don't know if I'm going to cross the boundary before I've hit the other end."
- "Rest aggressively AND compassionately!"
- "I use the Heart Graph App with the Apple Watch. After downloading the app, you can set the HR alarm within the app. I learned about it years ago from a Facebook group called **ME/CFS: Below The Threshold**. At the time, they had a guide to setting up Heart Graph w the apple watch."
- "For me it became plain and simple. I ask myself, 'Is this person with me? Do they care? Do they listen?' If the answer is 'NO', then I consider them OUT. It

may sound harsh but I've had to do that with even family. I am more peaceful now. Less conflict. Less stress."

- "Someone sent me this book below. I started looking at it and it sounds good so far. Just sharing as it is quite on today's topic. There is some good info on it online. It is on Amazon also. Book *Let Them Theory* by Mel Robbins
  https://www.melrobbins.com
  The Let Them Theory is a step-by-step guide on how to stop letting other people's opinions, drama, and judgment impact your life. Two simple words, Let Them ..."
- "Thought I would share the Spooniverse Directory, a comprehensive resource hub for patients and their caregivers to find clinical trials, healthcare providers, patient communities, and more:
  https://www.spooniverse.directory/"
- "We cannot educate everyone about our illness, it's not our job - especially because it's so exhausting."
- "I also don't like to talk much about it with family. I tell them I am doing the best I can but because of my life revolves around health challenges. I turn the conversation around and ask how they are doing and that works! They usually have a lot to talk about :)"
- "A book I've found very helpful: *How to Live Well w with Chronic Pain and Illness* by Toni Bernhard."
- "I'm reminded of that Ring Theory, of those closest to the problem, you comfort in. Those less close/not as involved, you complain out so as not to over-burden the inner ring person. https://psychcentral.com/health/circle-of-grief-ring-theory"
- "When I overdo it and end up in bed I tell myself that 'I just want to participate in life' and that is a real human need. Saying this over and over helps lessen the guilt and self-punishing thoughts…"
- "Here's another way to think about boundaries: Setting boundaries is to take care of yourself, not to change the other person, which usually doesn't work, anyway. You need to say NO, go to bed, get off the phone and so on. If you're thinking, but what if they...' use Mel Robbins' suggestion, 'Let them!'
- "I turned off location services and wifi and that has extended the battery on my Apple Watch so that I can use HR app all day - without running out of battery."

- "I space out calls, emails, to only 2 or 3 a week. Text is easiest on my energy. My mother is 93 so that is difficult because she can only do phone calls and refuses hearing aid; so I'm going to try FaceTime next time as it might be easier."
- I like Brene Brown's book and series called, *Atlas of the Heart*, to help give language and accurately name the emotion or feeling in a given scenario. Is it stress, or is it overwhelming? What are my tools?, etc. etc.

Resources for this session

- *The Untethered Soul*, by Michael: https://untetheredsoul.com/untethered-soul
- *The Let Them Theory*, by Mel Robbins: https://www.melrobbins.com/letthemtheory
- *The Atlas of the Heart*, by Brene Brown: https://brenebrown.com/book/atlas-of-the-heart/
- *How to Live Well with Chronic Pain and Illness*, by Toni Bernhard: http://www.tonibernhard.com/
- Spooniverse directory: https://www.spooniverse.directory/
- The Ring Theory: https://psychcentral.com/health/circle-of-grief-ring-theory

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.