Bateman Horne Center
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Support Group Recap: When People and Life Don’t Cooperate: Coping with Things Not Going the Way We Want Them to Go

October 15, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
    - https://batemanhornecenter.org/outreach/newsletter/
- BHC is co-hosting with Solve M.E. a free Severe ME Webinar Series
    - Register here: https://bit.ly/3Xa4IyW
    - Visit the playlist here: https://studio.youtube.com/playlist/PL-OZ_5Cqdc32kbu_2mKPi73TZDOQhDuab/
- BHC Research is 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 or endorsement.

Licensed clinical social worker, Timothy Weymann led this session. He began by introducing the topic and the discussion questions listed below.

Discussion Questions

1. What's an area in which you struggle with other people, your body of your life not "cooperating" with what you want?
2. What helps you cope with the uncontrollable?
3. What's a way of dealing with things not going the way you want that you have found to be unhelpful?
4. How do you access a sense of freedom amidst disappointment?
5. What do you wish you could learn to handle or do in facing a lack of cooperation from your body, life and other people?

Timothy’s shared wisdom:

- We can't control what other people think. A famous therapist said, "Are you in your business or theirs?" "Their business" is what other people think, and "our business" is what we think. Don't be waylaid by other people's perspectives but rather maintain your goal and match your behavior to your goal.

- Self-advocacy becomes very important when living with a chronic illness. In relationships, we often don't ask directly for what we want. An example could be to say, "Hey, will you listen to me for a minute; it would mean a lot to me." We always have the right to ask, and others always have the right to refuse. The more we can connect to our voice and use it the more powerful we can be.

- Dr. Victor Frankel taught that when we aren't able to change a situation, we are then challenged to change ourselves. What is my role in what's going on? How can I alter my behavior, attitude, or focus? That becomes our power and freedom.

- When we struggle with self-advocacy, it can mean (not always) that there is something underneath to address such as fear.

- Making friends. There are online platforms and groups that you can get involved in and make friends. Timothy made friends with people all over the globe during the pandemic through online groups. The BHC support groups are a good place to make friends. Timothy will let his friends know early on that he sometimes has to cancel and ask for their patience with him while encouraging them to keep asking him because it helps him feel included.
    - When we explain the reason behind why we ask for something the research shows the other person is more likely to do it.

- Talking to our bodies like a friend is a compassionate practice. When Timothy first became ill, he was angry and demanding of his body. He had an epiphany where he realized that his body was trying so hard amidst a challenge and that realization softened things for him. It brought more ease to dis-ease.

- Crisis can reveal problems that were already there in relationships such as lack of empathy. It's important to recognize this, otherwise, we can internalize it and resort to self-blame. In good communication, it's important to stay in observation without judgment. For example, "Hey, you said this. It affected me this way. Are you open to sharing with me more about that?" If someone says no, it lets us know that we need more boundaries with this person. Then we can re-direct our energy to finding someone more supportive and understanding.

- It can be helpful to realize that how we wanted our life to go was always only an idea and never a reality. When we focus on what "isn't" we miss out on what's here right now. People can struggle with acceptance when they have a dark narrative about what acceptance means. Some may not accept the illness as long as they tell themselves that it's unbearable or they won't ever have happiness. We need to mourn and also work to not be stuck by our better idea of how we think life should have been. Then we need to redirect to how we can honor what is important taking limitations into account. It can take creativity and flexibility to do this. Acceptance is an active rather than passive endeavor.

- If we are real with ourselves, nothing is ever certain. Normalizing that is helpful in general and in situations where others make statements about the certainty of our getting better. We can validate others by saying, "Thank you, I appreciate you trying to bring hope into my life and one way I feel supported is when you do xyz. Are you willing to do that for me?" This is a way to take ownership of the process and drive where you want the conversation to go.

- What happens in our life when we drop our blame? It is a disordered way to access control.

- Anger usually covers sadness, fear, shame, humiliation, jealousy. It can be helpful in pointing out the place that needs a boundary so we can further protect ourselves. Beyond that, when we come to our own personal healing, we can ask ourselves, "If I wasn't angry, what would I have to feel?" That is the place that needs nurturance and deeper attention.

- We do have to grieve relationships that aren't what we hoped they would be.

- There is an Eastern wisdom tradition called Daoism. With that is a practice called Wuwei, which is active non-doing. Rest is the act of doing – active not doing.

Participant Comments (statements in quotes are pasted from the chat)

- The participant is living with her mother and has a new apartment leased, but it has major noise issues due to the unexpected construction next door. She is receiving pressure from family about not moving yet.
    - The following was shared regarding noise issues:
        - Noise-cancelling headphones, white noise machines, and ear plugs are also available.
        - *Accessing the Healing Power of the Vagus Nerve* (book) addresses this to some extent, with easy-to-do exercises that can be done in a recumbent position. Stanly Rosenberg is the author.
        - "I recently bought two Bose noise-cancelling headphones, used from eBay. I decided to buy older models that have the old-fashioned wire set up, because I can just put them on my head and turn them on. The newer bluetooth versions were too complicated for me, but I'm sure they're great too."
        - "A few people I know (who have tried many options over the years) love Loop earbuds."
        - "Sony and Bose are both good brands for noise-cancelling Headphones."
        - Another participant had a similar situation and would use devices to help with the noise and learn to surrender to "what was."

- Participant has belonged to a book club for over 20 years. Some members recently indicated they don't want her to be a part of the group because she wasn't able to participate as much as she used to do. Others in the group encouraged her to stay. Participant decided to ignore the conflict with others in the book club. She realizes that having difficult people and situations is a part of life and that she can't control what others will think or do.

- Participant had an occupational therapist explain that she (participant) barely has the energy to hold the things she is going through and doesn't have the capacity to hold what others are thinking about her situation. Participant learned that she had to surrender what others think and "put it in the bucket."

- "Waking up in the morning, I 'go to my breath' and wait for the pandiculation to occur. That is the spontaneous yawn/stretch that gets me going."

- Participant is helped by finding coregulation by talking with others. She focuses on what she can control, such as if she can't control her health, she can focus on controlling her stride as she walks from one room to another.

- Participant moved to the opposite coast of where she was living and is trying to make a couple of friends to reduce the isolation. The challenge is creating new friendships where a lot of the time you can't show up. If people don't have a thread of experience with something they can try to understand but can't really know. I honor them for trying. I have very good friends on the East Coast and am in Zoom groups, but I am feeling a need for 2 or 3 people to go for a short walk or coffee with. Where I live, people are extremely physically active.
    - Additional comments regarding friendships:
        - Participant shares the following article with new friends to help them understand their situation: https://www.verywellhealth.com/dating-someone-with-fibromyalgia-or-cfs-4107210
        - "I was lucky enough to make a new BFF when she adopted one of my foster cats. It turned out she also had chronic medical issues and even though she lives in the same city as me, we don't see each other often, but we email and text almost constantly and we consider each other the bestest of friends. I love her and she me."
        - "When I'm in the company of someone else I always push harder than I should."
        - "I joined a local weight loss group, not that I need to lose, but I wanted the socialization...and it always helps to maintain your weight, to have a group in person. Once a week I can handle."

    - "Maybe a local affinity group, if you have any interests or hobbies, to help connect with new people. Do they meet up for short events or can meet up in a quiet spot for coffee and conversation?"

- Participant talks to her body parts. She doesn't have much control over her body anymore, so she lives in her head. She talks to each organ like they are a friend, putting her hands on her liver and thanking it for all that's it's done. Appreciating what the body *can* do is a way for her to have control over her situation.

- "I rolled my eyes at somatic therapy at first, but it has been so helpful for me. Just taking a step back and asking yourself how your emotions are manifesting in your body can be so helpful. And speaking kindly to yourself and your body is a wonderful tool to have in our arsenal."

- Participant finds that it doesn't work to try and convince people how bad her illness is.

- Participant would like to improve acceptance of what she is going through. She now has several co-morbidities on top of ME/CFS and POTs and is fighting against acceptance.

- "I took this FREE course a couple of years ago and 'graduated' from it. It has helped me tremendously as far as feeling better, dealing with my symptoms, radically accepting things I couldn't change, and showing compassion towards others and especially myself. I hope this will help all of you as well. It's called Mindfulness-Based Stress Reduction. Online MBSR/Mindfulness (Free) (https://palousemindfulness.com)"

- Unaddressed fear. Participant grew up with a narcissistic parent, so she feels like the bad guy when she self-advocates. She sees herself through others' eyes if they think she is a hassle. Participant finds parts therapy helpful in addressing these internal self-directed guilt feelings.

- Participant is newly housebound. Her family is rearranging her bedroom and living room to make them both areas where she can have people in to socialize.

- “Certain family members are ‘tired’ of my illness. They have become impatient with my lack of progress just because they recovered better than I did. (Long COVID). Sometimes they get mean.”

- “Grief counseling helped me deal with the losses in my life, including this condition.”

- “I am accepting the uncertainty of my condition, but my family and friends come with comments of certainty, which makes things worse for me.”

- Life is always a process until we are dead such as when we were kids, we changed what we wanted to do when we grew up. Participant learned to listen to others and see where they are coming from. She looks at the other person when they don’t understand and realizes that it’s their problem and not hers.

- “I was just reminded of things Brene Brown has said about the natural tendency to latch onto the negative, trying to 'win over' people. This also from Mindful magazine: ‘Pay attention to the people who are making themselves available to you. I’m not saying you should settle for spending time with people you don’t find interesting. But don’t seek out connections with people who don’t seem to be available to you.’ https://www.mindful.org/are-you-really-available-for-connection/

- “Here's a saying I made up that helps ME: ‘If you ain't got it, you don't get it.’ In other words, if they don't have ME/CFS (or anything else you personally struggle with), they cannot understand what you are going through. It's not their fault that they don't understand, so show compassion towards them. Sometimes, you have to get help and hope from whomever/whatever you can. If you see that someone truly wants to support you and doesn't mean you any harm, (which takes time to ascertain), hang on to them. Your intuition will tell you who/what to keep and who/what to let go. I've learned to trust my gut.”

- Thanks to this session I'm more motivated to do the things that I know will help.

- "Love the book, *How to be Sick* http://tonibernhard.com/"

General Resources

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.