Support Group Recap: Facing the Holidays with Chronic Illness

December 17, 2004

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 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 acknowledging that holidays are a time when there can be a lot of expectations, and grief triggered by the hallmark nature of traditions reflecting on our life. He introduced the following discussion questions to guide the session.

Discussion Questions

1. How do you honor the limitations and needs of your chronic illness amidst holidays?

2. What's a successful approach you've discovered that helps you healthily approach the holidays?

3. What kind of boundaries and expectations do you struggle with during the holidays?

4. What is your intention/goal as you experience the recent and upcoming holidays?

5. How do you communicate with friends, family, neighbors, etc. about your illness needs during the holidays

Timothy's shared wisdom:

- It's important to listen to ourselves during the holidays, especially when it comes with expectations from others.
- There is a concept of clean stress and dirty stress. Clean stress is related to things that we don't have control over such as our illness. Dirty stress is any way that we respond that isn't helpful or increases suffering. Expectations can become a form of dirty suffering. Managing expectations becomes an important skill. We must choose what matters most to us. Timothy posed the rhetorical question of, "How do I listen to myself regardless of what other people do or don't do?"
- If we don't accept ourselves, it's even harder for other people to accept us. Furthermore, if we don't advocate for our needs with ourselves it is hard to do the same with others.
- If you are hosting put people to work to help you. Be specific in your instructions.
- Creativity and flexibility are important skills as we face the circumstances associated with chronic illness. How creative can we be in our solutions to meet or partially meet our needs or a particular desire?
- There is a real place for us to make space in our hearts, to accept and adapt and grieve while there a losses and limitations.
- It's important to clearly communicate our needs and boundaries, especially during the holidays that often come with long-held expectations.
- Identify what matters most and organize our choices for the holidays around those important things.
- Invited everyone to cultivate a sense of hope amidst difficulty.

Participants' verbal comments

- Participant shared that she is quickly fatigued by guests and excuses herself to rest.
- Participant shared that her mother and sibling are begging her to travel several states away to visit them for the holidays. She decided to visit them at another time of the year when there is less holiday stress.
- Participant has been sick for four years and struggles with expectations because she still wants Christmas to be how it used to be and for her symptoms to magically go away for the holidays. The loudness and brightness that come with the celebration with her family is too stimulating. She is working on accepting where she is and adjusting to it.
- Participant shared that it took four years to accept that she isn't going home for Christmas. Now that she has accepted her limitations, she is getting creative such as doing a family Zoom and joining online hobby and friendship groups.
- Participant shared that she has adapted the holiday with her little grandchildren by hosting it outside (when the weather is nice). She can't tolerate the scents, so they put a little Christmas tree on the patio and have Christmas music as a background for opening gifts and stockings.
- Participant has two daughters who live in different states, and they connect by doing baking Zooms together. This year they will make a watercolor pen and paint of the same holiday scene.
- Participant shared that she keeps a sticky note on her computer with the letters WMI (What's Most Important). She asks herself what is most important and shares that for the holiday, it is the people she loves and wants to celebrate with. She starts with that and then decides what she can manage such as putting out just a handful of Christmas decorations and letting go of wrapping gifts if it doesn't get done. She puts out an advent calendar that she can do something small to participate in each day. The faith component of Christmas is important, so she joins an online service.
- Participant's therapist suggested that she look at the holiday as just another day. Such as another Thursday or Wednesday.
- Participant expressed frustration with a parent who won't provide her with a day and time that he will visit. This causes extra stress for the participant as she needs to plan when to wash her hair and other self-care so that she can have energy when they visit.

- Participant shared that it's helpful to treat holidays as any other day. He can travel in his RV if he gives himself plenty of time and goes slowly. Holidays have changed. If he is with his mother, they are satisfied with a meal and or watching a movie together.
- Participant shared that she experiences so much isolation it is challenging to make herself leave a social event before it causes PEM.
- Participant shared that she starts her day with gratefulness. She views this illness journey as her new chapter that she is discovering her inner introvert and being her own best friend.
- Participant refers to her illness as "the baby" such as "the baby needs to lie down" or the baby needs to be fed by someone else." This helps to remind the participant that it is not her fault.
- Participant shared that she is going through the diagnostic process and is learning about PEM. She wrote down guiding thoughts to help her:
    - Assume the Best
    - The only mind I can read is my own
    - Anything worth doing is worth doing slowly with many breaks

Participants' comments from the chat

- "I sauté apples with cinnamon and butter and add ground flaxseed to it and eat it warm with coco whip (dairy alternative, low sugar whipped cream)."
- "For us it's only a three-and-a-half-hour drive to New Mexico and hubby does all the driving. When I travel to Seattle, I always use the wheelchair service in the hospital and try and fly first class, so I have more room and a more comfortable seat. Thankfully, it's a direct flight, no stops. I do IV fluids before I travel for a couple of days in a row and that really helps."
- "I let my family know I can't cook, clean, or sit up for long periods. I volunteered to do some shopping, which I could do online and while horizontal, and contribute grocery money."
- "I don't travel anymore so that makes it easier for me to explain to my family, and myself. I have a few gifts sent online and if I can bake, I share it with neighbors."

- “I’ve spent the past year educating my siblings. They were more receptive than I expected and now understand why I don’t participate.”
- “It’s really hard, but you have to set boundaries. ‘I need you to stop guilt-tripping me a listen to my limitations. Next time you guilt trip me, I will hang up.’ It sucks to have to set those types of boundaries, but it’s part of treating yourself with respect.”
- “Always striving to ‘go where the love is,’ rather than feeling obligated to be with people who drag her down.”
- “My new video, Vulnerability Over Isolation, relates to the holidays and most days for me since I've been sick.” https://www.youtube.com/watch?v=WNqswG2Ypes
- “New favorite hack for decorating and easy to send gifts for others… EASY to set up, take down and store, no smell” https://www.freshcutpaper.com/?view=sl-C884732F
- “I don’t observe some upcoming holidays, and sometimes that amplifies the loneliness.”
- “This year, energy-permitting, I’m hoping to socialize more online. Gentle gathering with pauses for breathing and cognitive processing. Sharing a 15–20-minute cup of tea over Zoom with a chat or just sitting there.”
- “I find contentment in nourishing practices & some productive distraction activities: cooking a meal, reading and being offline for a day to recharge, revisiting my goals for the new year, signing a petition for a cause that’s important to me, and rest.”
- “I visit loved ones every year or so as I’m able, but one on one, not group celebrations. They know I love them.”
- “This conversation is great. I’ve been sick for over 15 years and have bumbled through the holiday seasons because everyone else I know pushes so hard and do, do, do. Expectations are high, especially as a woman in my circle of people. Your words are affirming that the limits I’ve implemented over the years are normal and reasonable for those of us with this disease. I now don’t feel alone in my simple holiday practices.”
- “I joined a ‘club’ at integrallife.com that has little classes where people can share and talk - it's kind of nerdy hobby, but the same people show up and it's semi-social...also I took another class and ended up meeting up weekly with a couple

of folks....so I guess taking a class and then offering to start a Zoom group with others when it's over....all online classes."

Session related resources

- Chronic Illness: What I Want You to Know

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.