Bateman Horne Center
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Support Group: Re-introducing Peace, Happiness and Joy to the Illness Experience

April 15, 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 began the session by explaining that he picked this topic to help interrupt rumination. Rumination is when we focus on the negative events in our life, their negative consequences and the associated feelings. Rumination can come into play in chronic illness when people fixate on the difficulties of the illness itself. This tendency is associated with declining mental health. Today's support group session addresses reintroducing joy and moments of peace into our lives.

Discussion Questions

1. How has illness affected your sense of peace, happiness and joy in life?

2. What brings you more peace or "ease" to your "disease"?

3. What ways are you introducing or re-introducing joy into your life amidst your symptoms?

4. What are the small things you are noticing in life that bring happiness, irrespective of your symptoms?

Timothy's Shared Wisdom

- A common theme that comes up in our lives is what do we do when people (or life in general) don't cooperate. We can examine how we approach that with a sense of peace and bring more ease into it.
- We don't need to approach art as an achievement or competition but rather how we process what we go through, how we share ourselves, how we enjoy ourselves. Some types of art can help us cope with what we are going through.
- Acceptance is a theme we revisit frequently to bring more ease to our dis-ease. We tend to think that if we tense against the challenges of life, it will pull us away from them, but instead, it can make things harder. We take a difficult time, and we amplify the suffering with that resistance. A lot of people find that they can tap into healing (not necessarily curing) by opening up to accepting life as it is.
- For those who are agnostic or atheistic, we can consider if we trust that nature is wise, that there is wisdom to the rhythm of nature.
- We tend to suffer when we have a small sense of identity of who we are and our identity becomes small when we are attached to what we do. We need to remember that we are bigger than anything we will ever do and bigger than anything we have ever gone through. Opening to that idea can be liberating and peaceful.
- We know from research that human beings are not good at predicting what will make them happy. A study looked at people who became paraplegic and people who won the lottery. It revealed that both groups of people would return to the level of happiness they previously had, like a happiness set point. Another study showed that the two predictors of happiness are quality relationships and losing a sense of self while doing something we really love, often called flow state. This can often be an interest of hobby that you are really enjoying while focused on the task. For those of us who are chronically ill we can focus on finding modifiable activities that we can keep trying and doing along with building relationships with people who can respect our needs and boundaries.
- Timothy references a play called *Angels in America* about HIV. One character says to the other, "deep inside you, there is a space entirely free of disease." Connecting to what really makes us alive and what we value can be an

uncorrupted pure part of us. As we do the work to connect to that and find activities that express that we can touch into that part of us.

- Losses and crises are also invitations for self-discovery when we work through the initial shock of what we are going through.

Participant Verbal Comments

- Participant shared that after her husband yelled at her this morning, she wrote a Haiku about the experience and posted it in a group with writers and friends. These kinds of strategies help her to keep hanging on.
- Participant shared that she works on genealogy to help get her out of a bad space. On days when she doesn't feel well, she finds something low-key to do, such as transcribing a record. It helps her to think about something besides the illness.
- Participant shared that she experiences insomnia so when awake at 4 am she can hear the birds start to sing and this has brought happiness irrespective of her symptoms.
    - Her illness shattered her sense of peace and happiness. She has been angry at it. Screamed at it. Depressed about it. Yet, it's still there no matter what. She decided that she still gets to wake up every morning and think what do I get to do today that can bring a little bit of peace, joy, and happiness. She speaks to her higher power, and it helps her to have something bigger than herself.
- Participant shared that she has been experiencing depression for the last few weeks and is working towards being in touch with her emotions and her body. She bought Play-Doh and went back to playing like a child to do something fun. The aroma of it brings her back to childhood. It is helping her to be in the moment and experience appreciation.
- Participant shared that she was recently excluded from a book club because she can't host and cook meals for everyone like the other members. It brought back all the sorrow of having this illness. She has decided to spend more time outdoors where she always finds something inspiring like the flowers and trees blooming.
- Participant shared that she was an IT Manager and the breadwinner for her family because of her husband's disability but then becoming ill herself

challenged her identity. She expressed relief at now finally being able to distance herself from the feelings of guilt over receiving disability payments and instead enjoy being away from the high-pressure job. She is starting to allow herself to feel joy.

- Participant shared that she was a retired power lifter and runner before becoming sick with Long COVID. Surrendering was the first piece. She exhausted herself and became bedbound. She had to hope that something outside of herself would take care of her and accept her new existence. For several years the only thing she could see out of one bedroom window was a tree. She focused on the first leaves in the spring, and squirrels or birds playing in the tree to give her hope that life was continuing. Now she has a power wheelchair and can appreciate the crocuses blooming and dogs on a walk. She used to go through life on full throttle and now she sits back and looks for the small things to enjoy.
- Participant shared that for 3-minutes each day she performs a few basics steps of the Latin dance called bachata. She does this while lying down, sitting, or sometimes standing. A former health practitioner suggested that she find peace and cope with her symptoms by remembering the times when her body temporarily recovered.
- Participant shared that finding music that matches how she feels helps her to release emotions. She then follows it with something uplifting that helps her to feel hope.
    - She also shared that Internal Family Systems therapy modality has helped her.

Participant Chat Comments

- “Definitely more difficult to find peace since becoming ill. But this makes when you do feel peaceful, it so much more appreciated.”
- “1. Peace. Seeing a rating scale for the first time ... it made me know this illness is real and that there was a way to measure it.”
- “In some sense ‘giving in’ to this disease and living within my limits has brought more peace and ease into my life. Even though that means I am bedbound the

majority of the time. I fought it for a long time and continued to push past my limits. Life is more peaceful now.”

- “I used to not allow rest or fun until all the work is done. That won't fly anymore!”
- “May have to look for happiness, joy, and peace in different places than you did before. Be open to the kindness and support of others.”
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- “One of the things I have been doing when I am so housebound and bedridden at times is to have a table and get out many pictures of the years of my kids...of my soldier son, my daughters and grandchildren, great grand, and go through, edit, and have some restored a little at a time. I have such joy at looking at them.”
- “I’m taking an on-line writing class that’s a lot of fun.”
- “My definition of joy, peace and happiness has changed drastically with this disease. I look for the little things in life, most of which God has given us, nature, music, art, friendships, etc. Hoping you can find what brings you peace!”
- “Getting out in nature can help with peace and joy, even just watching the birds in my yard.”
- “I have a small yard and am focusing on watching what lives there, plants, birds, bugs, and photographing and writing about them when I can.”
- “Mindfulness practice enables me to be aware of negative thoughts and choose not to follow them, Also, daily gratitude practice. Even appreciation for the small things: my comfy bed, having a home, etc.”
- “I couldn't sleep a few nights ago, and it was neat to hear the birds wake up and start singing to each other in those pre-dawn hours. It made me feel not so alone.”
- “I go through a cycle of emotion I imagine other do too. Frustration, Resentment, Anger, Hopelessness, and then I get hope that maybe something we help, try new things, follow suggestions and periods of happiness and cycle again. Wishing everyone Hope 💕”
- “I am trying to develop a "self-care menu" to help choose a practice and adapt to whatever I might need in the moment. I appreciate these ideas Jeannie Di Bon shared this week:

  - "Soothing the senses is one way to soothe the nervous system.
    When living with hypermobility, pain, or fatigue, our senses can become hypersensitive. Here's how calming each one helps us return to balance:
    Sight: Soft lighting and natural colors reduce visual overstimulation.
    Sound: Gentle music or white noise calms the auditory system and supports vagal tone.
    Touch: Weighted blankets, soft fabrics, and gentle self-massage provide grounding sensory input.
    Smell: Essential oils like lavender or frankincense can activate the parasympathetic nervous system.
    Taste: Warm, nourishing foods can regulate digestion and offer comfort."
- "As a young, type a, athletic person now trapped in this hellhole - I keep a daily checklist of things to do (big and small), so every day I can check things off and feel accomplished. As simple as wash face, meditate 5min, hug my dog, and more."
- "I really like the Todoist free app, so I don't lose track."
- "I love lists! Sometimes if I do something that's not on my list, I will sometimes write it down, just so I can cross it off!"
- "I love the 'easy list' (mine is easy) and I feel like a GRAND CHAMPION when I do these items, 'heck yeah, I dusted' (barely - but still a champion!)"
- "I use a fun Finch Care app that lets you get 'points' for completing ToDos and a pet bird to dress up and set up a bird house for. You can connect with friends on it. It sounds silly but it motivates me to get through mundane tasks. It also has breathing exercises and gratitude prompts."
- "I have a Behavioral Coach; she helps a lot. Creative activity increases endorphins and helps you take you away for a bit. I can no longer do the oil painting, jewelry making etc. So, I found something I can do from bed. New Hobby I am excited about Needle Felting animals and birds, flowers."
- "As the recent speaker said nostalgia can provide a lot of joy. I have been watching old TV shows I watched as a child. Sitcoms in particular provide a dose of humor and nostalgia at the same time."
- "Helps to find a hobby that you can do from bed or doesn't take too much energy, could be crocheting, poetry watercolor etc. I found needle felting which I can do from bed 😊"

- “I love reading! It's the biggest thing that keeps me from falling into the despair of my illness. If anybody is on StoryGraph and wants to be friends, my username is KPKP”
- “I paint with watercolors for 5minutes a day. It’s lovely. And if I skip a day/week/month, it’s fine. Whatever I get done is great. And I keep the paint out on the desk, so it just makes me happy to see it. There’s almost no clean up (you just rinse the brush in clean water for a few seconds [unlike acrylic paint, which takes a few minutes to clean with soap and water])”
- “Nura Community has a virtual book club. https://www.nura-community.com/”
- “It’s interesting, funny, sad, how just showering and washing your hair can be such an accomplishment. I always feel so proud of myself. It wipes me out for the rest of the day, but I did it!”
- “I’ve found that I interrupt my ruminations by texting a friend to ask how they are.”
- “Atlas of the Heart by Brene Brown checked out of Library. Really helpful explaining Emotions. Big Difference between Joy and Happiness. I experience moments of happiness not sure about Joy.”
- “Song and Dance always makes me happy. The Black Crows - Lonely Boy is awesome! 😎 Watch the video - so great!”
- “I wrote a welcome note to a new neighbor, along with a bunch of daffodils that just bloomed. She was so pleased, which gave me great joy! Doing something nice for others is always a burst of happiness!”
- “Inner Child work is great. Steven Halpern has wonderful music album called “Music for your Inner Child.” ☀️
- “IFS (Internal Family Systems) book. It helps is identify our protectors and exile inside ourselves. It is self-discovery and learning to understand, love and accept ourselves. It has a workbook also. This has helped me greatly!”

Tiny Triumphs

- “Today I waved to a neighbor, which usually I don't do.”
- “I survived another trip around the sun. Today is my birthday.”

- “I became a patient of a pulmonologist who studied with Dr. David Systrom (in Boston). He knows all about ME, POTS, etc. and is taking it into consideration for the tests he’s ordered.”
- “My over the bed desk arrived and was able to brush my teeth and do some basic skincare from it. I got it from the UK Amazon so it may not be useful for those in areas outside Europe. https://bit.ly/3SrHFNa”
- “Bought another fan to help cool my bedroom. It’s working:-)”
- “Able to shower and wash my hair today ! 🙂 ”

Resources

- Parenting with a Chronic Illness BHC video (2016): https://youtube.com/live/S7IAY363Lww
- Book review on new book about disabled parenting by a woman with EDS and POTS: https://wapo.st/4j3Tkxa
- *Twirl with Me Mama”* by Melissa Beardall. A book for children who have a parent with Long COVID.

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

- Action for ME (online youth support based in UK)
  - https://www.actionforme.org.uk/18-and-under/support-for-under-18/join-our-young-peoples-community/
- 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/
- Utah COVID-19 Long Haulers
  - https://www.facebook.com/groups/2619858348232191

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.