

Lunch & Learn Recap: My Favorite Things

December 19, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
 - o <u>https://batemanhornecenter.org/outreach/newsletter/</u>
- BHC Research is recruiting for two Long Covid studies. Visit <u>https://batemanhornecenter.org/research/</u> to apply or for additional information.
- Lunch & Learn series is open for presenters. Email <u>outreach@batemanhornecenter.org</u> if you are interested in presenting to the BHC community.

Comments and questions from participants do not necessarily reflect BHC guidance or endorsement. Lunch & Learn topics are selected by the lived-experience presenter.

Participants were divided into break-out rooms of four to five people where they shared their "favorite things." The rooms were "shuffled" every 20 minutes, enabling conversation with new people. The following is a list of items shared by participants.

- Magic Gel Migraine Ice Head Wrap
- Long COVID & ME/CFS healing through creativity Facebook group
- The Visible app
- Ultima Replenisher Daily Electrolyte Drink Mix
- Countertop oven
- Painting
- Rollator
- <u>Russell & Hazel organization items</u>
- The Five Love Languages by Gary Chapman
- Favorite author is Meghan Quinn for light erotica
- Through Fire and Grace book
- Online shopping for groceries and everything else
- Car door support handle
- Door ramp that lets me get on my patio safely



- A grabber in almost every room, plus this one for travel because it folds
- <u>A dry-erase board calendar for planning pacing</u>
- Self-made ornament, star quilting pinned on a Styrofoam ball (Wish I knew the name of the technique. It has many fancy layers and pockets.)
- Genealogy, painting—can be done a few minutes at a time
- Puzzles and accessories—sorting trays that stack (as many as 18), puzzle pad (with 2-piece top) that can be stored under bed, easel for a picture of the complete puzzle, lamp
- Animals, including dogs and cats seen on screen in this Favorite Things session
- TV as a window to the outside world
- Temporary hair dye
- Ice pack that stays cold or 5-8 hours, <u>Cryomax</u>
- Electric blanket, heating pad, humor/jokes, particularly spoon jokes
- Scary movies, psychological thrillers
- Season 4 of All Creatures Great and Small for being the opposite of scary
- YouTube
- Direct sunshine seems to help with mitochondria and ATP production
- Sitting outside
- Sunsets and sunrises
- Migraine ice pack hats, at least 2, so there's always a replacement waiting in the freezer
- Drive-through events, like holiday lights in a park
- Driving to a park and watching birds
- Seeing holiday carolers
- Beading as art
- Bateman Horne Center
- Finally getting a diagnosis
- Support groups
- List of friends/family and providers who believe me and understand, at least a little, to look at when I feel like no one understands or cares
- Providers who understand
- A delightful low-maintenance windowsill garden, to replace gardening outside
- Biofeedback devices such as bands and watches for heart rate variability to use with apps like Visible and Welltory



- Olive & June nail polish and hand care
- Ella & Mila nail polish, water based, good for those with MCAS-no histamines
- <u>Loop earplugs</u>
- Smasta standing pencil case/phone holder
- Remote operated color changing lights
- Candles
- Tea
- Special blanket
- Homemade electrolytes: for 1 liter of water, add 1/4 tsp of salt or salt lite (potassium) and 3/4 tsp of baking soda
- Life with a Low Battery: Living with ME/CFS YouTube video

General Resources

Crisis Resources

- Dial 988
 - <u>What Happens When You Call 988?</u> (Article)
- Dial 911
- <u>Crisis Text Line</u>
- Crisis resource page (BHC)

Support Groups (alphabetical order)

Lived-Experience Support Groups

- BHC Support Group 2nd and 3rd Tuesday at 1 pm MST
 - <u>https://batemanhornecenter.org/events/</u>
- Black COVID-19 Survivors
 - <u>https://www.facebook.com/groups/bcsalliance/</u>
- CFS/ME Friends
 - o <u>https://www.facebook.com/groups/CFSMEFRIENDS</u>
- Health Stories Collaborative Creative Meetups
 - o <u>https://www.healthstorycollaborative.org/creativemeetups</u>
- International ME Support Chat



- 11am-1pm EST/ 5 -7pm GMT / 3-5am Melbourne time & 9-11pm
 EST/ 3-5am GMT/ 2-4pm Melbourne time
- <u>https://us06web.zoom.us/j/84362703704?pwd=bfKmegaCLNhS6Kw</u>
 <u>OUve7fkcsQjs7sB.1</u>
- Invisible Youth Support Group
 - https://www.facebook.com/groups/invisibleyouthgroup
- Long Hauler Advocacy Project
 - <u>https://www.longhauler-advocacy.org/support-us</u>
- Long COVID Families
 - o https://www.facebook.com/groups/4345929175466216
- Massachusetts ME and FM Association Small Group Chats
 - o <u>https://www.massmecfs.org/</u>
- #MEAction Living w/ME Support Group
 - o https://www.facebook.com/groups/211058135999671
- #MEAction Long COVID Group
- <u>https://www.facebook.com/groups/205703087068863</u> #MEAction Seniors

Connect

- <u>https://www.facebook.com/groups/391269901334695/?ref=pages_pr</u> ofile_groups_tab&source_id=1408335399448862
- #MEAction Pillow Crafters (Group Crafting Sessions)
 - https://www.meaction.net/pillow-crafters/
- #MEAction Additional Groups
 - <u>https://www.meaction.net/groups/</u>
- ME/CFS Social Group
 - o 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
 - <u>https://docs.google.com/spreadsheets/d/1vMNCrONg1oTy5QPzaj</u>
 <u>NUJffu0gk4eBR4o585NosVgsk/edit#gid=0</u>
- Surviving with ME
 - o https://www.facebook.com/groups/695317212152964
- The Mighty Group Directory

<u>https://themighty.com/groupdirectory/</u>

• 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

• <u>Caregiver Wisdom</u> is an online venture to support chronic illness caregivers. <u>Current free offerings</u> include: a <u>monthly support group</u>, a <u>free online community</u> that's off of social media, and <u>a blog</u> 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 <u>caregiver@meaction.net</u>.

- If you are on Facebook, <u>#MEAction has a Facebook group for caregivers</u>
- If you are on Discord, Nia has started a <u>channel for ME/Long COVID</u> <u>caregivers.</u>