

Lunch & Learn Recap: Staying within Your Energy Envelope by Modifying Tasks

May 16, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
 - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is still recruiting for two Long Covid studies. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.
- Lunch & Learn series is open for presenters in 2024. Email outreach@batemanhornecenter.org if you are interested in presenting to the BHC community.
- Latest newsletter: <https://batemanhornecenter.org/wp-content/uploads/2024/03/Winter-2024-newsletter.pdf>
- Please note the support group date changes for June and July:
 - Friday, June 7th from 1:00-2:00pm, MT
 - Friday, June 21st from 1:00-2:00pm, MT
 - Tuesday, July 16th from 1:00-2:00pm, MT
 - Tuesday, July 30th from 1:00-2:00pm, MT

The following presentation summary, resources, and anecdotes were shared by attendees and do not necessarily reflect BHC guidance nor endorsement.

Amy Mooney, MS OTR/L is an occupational therapist who works with Bateman Horne Center (BHC) on a variety of educational work, and she has a young adult daughter with severe ME/CFS.

- View video recording of [Amy's presentation here.](#)
- [View presentation slides here.](#)
- [View Amy Mooney's resource list here.](#)

Presentation

- Symptoms change over time.
- How do you manage the unknown regarding the amount of energy that you can expend each day?
 - Metaphor – what kind of iPhone are you using each day (ex. iPhone 2, vs iPhone 5 vs iPhone 10? When apps require more than the platform can handle, you need to start removing apps. Need to prioritize what your body (or platform/iPhone) can do that day. Plan ahead for what is happening that week/month/etc.
 - Credit card analogy – what is your budget for the day?
 - If low, know that each activity will use up a portion of the budget.
 - What is the cost for exceeding your balance?
 - Know that you will need a lot of rest if exceed your balance.
 - How many buckets do you have?
 - Physical tolerance/physical exertion
 - Cognitive exertion
 - Social/emotional exertion
 - How full is your bucket?
 - You may be able to walk around your kitchen, but can't hold a conversation or look at a recipe.
 - Will need to prioritize activities that are meaningful and that you can do without PEM.
 - Symptoms
 - It's important to understand your warning signs or symptoms in correlation with exertional triggers.
 - Avoid the "boom-bust" or "push-crash."
 - What are your stop signs? See the slides for the chart.
 - Use symptoms to know when you need to stop.
 - Look at physical exertion, cognitive exertion, social/emotional exertion.
 - Example of warning sign(s): word finding issues, difficulty processing information, heart rate increases, etc.
 - Delayed response
 - For same three categories (physical, cognitive, social/emotional).
 - Once you have order and are able to prioritize activities, you gain a little control and decrease the unexpected.

- Each bucket has an individual threshold for tolerance.
 - Example: physical exertion may be 50% full, so consider doing something cognitive instead to preserve remaining energy envelope.
- Task and activity analysis can be helpful.
- ADL (Activities of Daily Living)
- IADL (Instrumental Activities of Daily Living)
- Amy works on looking at tasks and breaking them down or modifying to conserve energy wherever possible – see slides

Discussion

- Is there a way to resolve this long-term?
 - Billion-dollar question.
 - Take mental snapshots of what triggers the body the most.
 - This disease is a marathon. While many things cannot be fixed, gaining some control back and limiting the deep crashed periods will improve quality of life.
 - Comments from the chat:
 - A list of recovery stories here: <https://cfsunravelled.com/move-forward/>
- OT question – can you wash your hair without being in shower, etc.?
 - With caregiver
 - Amazon blow up neck pillow washing basin.
 - Use watering can, with patient laying on bed.
 - Put garbage can at the end of the bed to capture water; make sure basin drains at the end of the bed.
 - Try washing hair in sink.
 - Suggestions from the chat:
 - Try a complexion brush to dab it on and then rub in or brush through.
 - A brand called K18 makes a dry shampoo that is in liquid spray form. Despite it being liquid, it's not supposed to interfere with styling and it actually tackles odor and keeps working for 3(?) days. It's a splurge... about \$50. I've used it a few times and really like it. I'm hoping the bottle lasts a while!

- In the UK we have a company called freshwipes. They have shower caps with shampoo inside. They are for one use. I believe you don't have to rinse
- https://www.k18hair.com/products/airwash-dry-shampoo-4oz?gad_source=1&gclid=Cj0KCQjw3ZayBhDRARIsAPWzx8rur9MCUnGOPLZjbQvITTA7I70pNS760Xlh7aL59u6_uzwcACitlX8aAkBjEALw_wcB
- If you're interested in dry shampoos, there are some without butane (you just shake the bottle and squeeze it for the shaken-up powder to come out... I think Klorane is a common brand that may have some like that.)
- lume and wipes are my go to for staying clean
- Depending on your hair/scalp, you can also try wiping your scalp with a cotton pad soaked with a bit of witch hazel (I would get one without alcohol), or adding a drop or two of Castile soap (it's non-foaming) on a very damp washcloth to wipe the scalp and top of hair, then repeat with just a clean damp cloth.
- When becoming more and more fatigued or impaired due to PEM onset/presence:
 - Can you ask someone to intervene on your behalf?
 - Have a more prepared social engagement, knowing topics to prioritize, set a time limit and being strict with it. Use timer or someone as a gatekeeper.
 - It's easy to get carried away with conversations and engagement.
 - Can be overwhelming.
 - Prioritize topics that you want to talk about.
 - Ask if you can share your thoughts first so you don't forget it.
- If do all these things and are careful, but stuck in a crash and not coming out of it? Can you improve from this?
 - The activities you are doing are down to the foundation of survival at this point.
 - In bed (quiet, dark room/low sensory, temp control)
 - Focus on getting nutrition and manage your body functions.
 - Stay within this boundary.
 - Recognize where you are at and don't push in any way. Really listen to your body's cues
- Is it common with this condition to have panic attacks?
 - Yes, can have panic attack with any condition, even those without health conditions.

- Often misunderstood that people with ME can have POTS, and that can feel like you are having anxiety or a panic attack (part of the dysautonomia).
- Tips on [pacing upright activity](#) (BHC handout).
- Using heartrate and heartrate variability to pace? Calculations to use? How to use?
 - These are useful tools for monitoring physical activity.
 - [WorkWell Foundation](#) has handouts on heart rate pacing. Keep in mind the other stressors/buckets that can cause PEM (cognitive, social/emotional, sensory/environmental).
 - [BHC HRV handout](#).
 - Important to tie your symptoms to warning signs of overdue.
- When going on a trip with healthy people. How do you stay focused on what you need to do?
 - Plan.
 - Allocate energy to car ride, walking, navigating town, etc.
 - Bring headphones and comfort items.
 - Let others know when you need to break.
 - Schedule in breaks.
 - Car with A/C/ or heat on, reclined, quite space.
 - Detail what the goal is:
 - Walk on beach – goal may be to see beach.
 - Schedule pr-emptive and recuperative rest
 - Noise minimizing/cancelling
 - Earplugs: Loops
 - Bose headphones; can be pricy.
 - Aside from volume and disruption, there's the cognitive load of not being able to filter or process. Using a white noise or pre-emptive focus can help.

Resources shared by participants and BHC related to the topic

- Clayton and Amy gave a really great presentation in December that includes much of this information.
 - <https://youtu.be/9vfOZzILsAU>
- *Managing Chronic Fatigue Syndrome and Fibromyalgia* by Bruce Campbell
- The [BHC Rehab Professionals page](#), while geared toward healthcare/rehabilitation professionals, is also intended to help patients with pacing and avoiding PEM. Here are

a few short and informative handouts:

<https://batemanhornecenter.org/providers/mecfs/diagnosing-managing/rehab-professionals/>

- What is PEM/PESE?
 - https://batemanhornecenter.org/wp-content/uploads/2023/05/What-is-PEM-PESE-05_2023.pdf
- Understanding the Push/Crash Cycle
 - https://batemanhornecenter.org/wp-content/uploads/2023/05/Push-Crash-Cycle-05_2023.pdf
- Pacing for PEM
 - https://batemanhornecenter.org/wp-content/uploads/2023/05/Pacing-for-PEM-PESE-05_2023.pdf
- Pacing Upright Activity
 - <https://batemanhornecenter.org/wp-content/uploads/2023/12/Pacing-Upright-Activity-Handout-1-002-20231207.pdf>
- Energy Conservation Tips
 - <https://batemanhornecenter.org/wp-content/uploads/2023/12/Energy-Conservation-006-20231206.pdf>
- Heart rate pacing: Workwell Foundation Handout
 - <https://workwellfoundation.org/wp-content/uploads/2023/01/HRM-Factsheet.pdf>
- Pacing and Management Guide for ME/CFS (#MEAction)
 - https://www.meaction.net/wp-content/uploads/2021/02/Pacing-and-Management-Guide-for-ME_CFS-9.pdf
- Orthostatic Intolerance (basics)
 - <https://batemanhornecenter.org/wp-content/uploads/2023/09/Orthostatic-Intolerance-Education-Handout.pdf>
- 10-Minute NASA Lean Test Instructions
 - https://batemanhornecenter.org/wp-content/uploads/filebase/providers/mecfs/10-Minute-NASA-Lean-Test-Clinician-Instructions-06_12_2022.pdf
- Dysautonomia information at the Cleveland Clinic
 - <https://my.clevelandclinic.org/health/treatments/23555-autonomic-dysfunction>

General Resources

- Crisis Resources
 - Dial 988
 - [What Happens When You Call 988?](#) (Article)
 - Dial 911
 - [Crisis Text Line](#)
 - [Crisis resource page](#) (BHC)

- Support Groups
 - BHC Support Group 2nd and 3rd Tuesday at 1 pm MST
 - <https://batemanhornecenter.org/events/>
 - Surviving with ME
 - <https://www.facebook.com/groups/695317212152964>
 - ME/CFS Social Group
 - <https://www.facebook.com/groups/1202428297198122>
 - CFS/ME Friends
 - <https://www.facebook.com/groups/CFSMEFRIENDS>
 - 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>
 - ME/CFS phone support group
 - Occurs on Saturday nights at 8pm, EST.
 - Call: 609-746-1155. Punch in: 915110#. Group is open to all.
 - Massachusetts ME and FM Association Small Group Chats
 - <https://www.massmecfs.org/>
 - #MEAction Living w/ME Support Group
 - <https://www.facebook.com/groups/211058135999671>
 - Caregiver Support Group
 - <https://www.meaction.net/event/me-partner-caregivers-support-group/all/>
 - Health Stories Collaborative Creative Meetups
 - <https://www.healthstorycollaborative.org/creativemeetups>

- 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**. We focus on monthly topics and have 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](#).