

Support Group: Getting Unstuck in Stuck Places

April 8, 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 started the discussion by sharing a quote from the famous psychiatrist Dr. Viktor Frankl, “When we are no longer able to change a situation, we are challenged to change ourselves.” That can be part of getting unstuck from the stickiness that we find ourselves in with things we can’t control.

The following questions guided the group conversation.

Discussion Questions

1. What are some life areas in which you feel stuck due to chronic illness? Are there patterns you notice?
2. What helps you access liberation amidst the uncontrollable?
3. How do you develop a sense of power amidst disease?
4. What are novel and creative ways you’ve problem-solved chronic illness struggles?

Timothy's Shared Wisdom

- In response to a question about how to become more flexible Timothy explained that we can become hardened or attached to the idea that the only way to have a meaningful life is by being cured. We can address flexibility and rigidity at its core by opening up to the idea that we can have a meaningful life while living with chronic illness. Our flexibility can increase by identifying and then challenging the ways we are attached and narrowly defining success, happiness, or peace. Holding onto rigidity can also be a form of defense. We get anxious and we are coping with life by tensing against it and tensing against our illness. This tends to make us feel smaller, trapped, and fuels internal suffering.
- It is important to keep returning to the self when dealing with stuck places and difficult things. We can ask ourselves what is working and what do we need to advocate for ourselves. We must become our own best self-advocate.
- Part of psychological flexibility is that we are open to how we achieve a particular goal. If we must give up on a goal such as going to school or work we can identify what that goal represented and then explore another way. For example, if self-development was the value for pursuing education, we can look for ways to achieve self-development that is not formal schooling. This process can be a path to getting unstuck or flexibility.
- In response to a question about how to deal with the ever-shifting and worsening of illness, Timothy acknowledged that we may be limited in a certain area or moment in time, but that we can still work on how we are holding narratives of powerlessness or hopelessness. We can work on how we frame what we are going through, even from a hospital bed. We can inquire within ourselves if we are open to the experience of the situation, such as being in a hospital bed. Are we curious about it? This is deeper work that healthy people aren't as invited to do it as we are.
 - We still must practically solve the logistics but there is a parallel process of how we conceptualize our experience and how open-hearted we are becomes an important question.
 - Anxiety is rigid, it collapses, it makes us small. We are tense against things thinking that we are protecting ourselves. Let's challenge the things we are afraid of. Is it true that we are incapable emotionally, mentally spiritually, of facing hardship?

- In response to a question about planning for the future amidst changing illness, Timothy shared the quote by John Lennon, “Life is what happens to you while you’re busy making other plans.” There is a kind of illusion of control over our life that is shattered when we become chronically ill.
 - When we accept that the nature of reality is impermanence, that we can’t predict, we can relate to what others go through differently.
 - It’s possible to lose our rigid grasp on our ideas about how life must be in order for us to be satisfied. We can build bigger hope that no matter what happens, even if I don’t get my outcome, I’ll make life meaningful and purposeful. This is an opportunity to expand our definition of hope.
 - We can work on adaptive plans that incorporate instability. Part of it is the acceptance piece of what is possible for us in our waxing and waning moments of health circumstances.
- Sometimes life gives us a bad choice, and a less bad choice and we have to suit up and face that. When choosing, we can think in terms of which option do we feel will be the best for us and then empower ourselves in that choice.
- All humans are mortal and thus face limits. We can tend to harden and tense against them. There is a thought that internal freedom from stuck places comes with the moment that we accept “what is” without resistance or judgment. Examine how we can relate to limits in a way that keeps us open-hearted. Keep giving yourself the grace that you are doing the best you can in a difficult situation and keep trying new approaches.
- People with these illnesses have a higher risk of developing PTSD. One symptom of trauma and anxiety is rumination (repeating mentally and verbally all the negative things that have happened to us). This is a stuck place that we can keep working on by identifying what we can do to face living with chronic illness.

Verbal Comments

- Participant shared that she is just learning that she is on the autism spectrum. She is discovering that her empowerment is the freedom to unmask from autism and tap into what her intuition and authentic self are telling her instead of other people. It comes down to what kind of treatments or tests are best for her and what she is willing to endure.

- The participant shared that he has become better at dealing with the process of seeing various specialists and receiving unhelpful test results. He knows what he will or won't tolerate and no longer believes that any one appointment or test is the last option to figure something out. When he slips into a distorted way of thinking, a daily practice of gratitude and staying connected to community, relationships, and acceptance gets him through. He now challenges the victim point of view and self-advocates by learning to connect with resources. Creative problem solving comes as he has learned to be teachable and open-minded. Instead of automatically thinking that a suggestion won't work for him, he will try some things.
- Participant shared how after no longer being able to work she redefined what community meant to her. This support group, regularly listening to podcasts, and supportive healthcare workers now define her community. She also mentioned a book called, *Classic Pacing for a Better Life with ME*," by Ingeborg Dahl has helped her to understand pacing.
- Participant shared that when he has a problem with something, he tells himself to "stop and it's okay" because his brain isn't successful at forcing things.
- Participant shared that she has spent thousands of dollars trying to find a cure and thought that she would be better by now. She explains having to humble herself and instead look for what she can learn from others about chronic illness. She expressed appreciation for learning about the spoon theory, pacing, and how writing can be therapeutic. When she attends a meeting, she writes down notes of what she learns to help her stop compulsively going past her level of fitness.
- Participant shared that tracking her sleep and heart rate helps inform how she paces.

Chat Comments

- "Acceptance and Commitment Therapy has been very useful to develop a sense of identity and quality of life with my Long Covid/CFS"
- "My favorite saying that keeps me going: 'Life Isn't about waiting for the storm to pass. It's about learning how to dance in the rain.' Vivian Greene"
- "My power chair makes it possible for me to maintain my independence. I appreciate that it gives me a sense of power over my own life."

- “For me shifting and viewing life thru an updated lens/a different perspective helps me cope with chronic illness. Changing expectations, what is a “win” and having MORE self-compassion assist me accepting this alternate path.”
- “I think in some cases the illness damages flexibility in a direct biological way or in any case it's a thousand times harder than it is for a healthy person. Having energy makes flexibility much easier. I think one needs to be easy on oneself for needing routine and other specific needs even when others may complain.”
- “I hear THAT about autism/neurodivergent unmasking after a LIFETIME of trying to fit in, finally getting some proper diagnosing after DECADES.”
- “I'm late-diagnosed as autistic too. But doctors kept dismissing me as 'just depressed' for years too. I now believe many doctors were quickly noticing autistic traits (body language, etc.) within the first minute or two of the appointment, and then they're so certain that *any* other symptom I have will be psychosomatic, so they don't even ask any questions or take a history about it. Writing out an autism 'health passport' (with extra info) seems to be helping so far.”
- “I have become stably unstable in my illness (I know better how to cope with the day-to-day changes)”
- “The future is so unpredictable! And also feeling like setting ‘goals’ can be setup for disappointment, yeah that's hard.”
- “Quote by Victor Frankl – ‘We cannot control what the world does to us, we can only control how we respond.’”
- “For people with overeating type issues, groups like Recovery Dharma (Buddhist approach) or 12 Step groups like Overeaters Anonymous can be really helpful. Lots of Zoom meetings.”
- “Another coping mechanism for me is understanding two things can be true at the same time. Yes, I'm sick but I have gifts to offer, I am not following the path I thought I would, but I am here and get to see my family, I can't do certain things BUT I can do others. Yes, my body is imperfect, but it's working as hard as it can.”
- “Timothy's John Lennon quote reminds me of the saying, ‘Man plans, God laughs,’ which is the title of my Long COVID back story video: <https://www.youtube.com/watch?v=I1DvKnZT-OY&t=567s>”
- “This site might help, has a variety of tools and tips <https://cfselfhelp.org/>”

- “Here’s the Goodreads link <https://www.goodreads.com/book/show/42737771-classic-pacing-for-a-better-life-with-me>”
- “I always go back to what Meredith said about using your spoons wisely. I've come to not use my spoons on things I can't control. I won't use any for anything negative. The little energy I have, that changes daily, is too precious to squander on anything that is not productive and helps me in that moment. I now know when I decide to use all my spoons on a task it will be well worth the crash that will result.”
- “The other thing that was very hard to come to terms with is I'm not my old self anymore, stop comparing now to then. My life now is in super slow mo. I'm not a 'normal' person anymore. That doesn't mean I can't live my life like I want. It just means the timeline on things I can do are extremely extended. I might not be able to do things I would've normally planned on doing in the past but I still can do them... eventually and in smaller doses.”
- “Jennifer Piercy is great on Insight Timer, her guided yoga Nidra tracks are so relaxing.”
- “On question 4, I've been trying to find ways to make life easier/more accessible by getting cheap aids. So found a cane for 10 bucks (local online classifieds sellers who deliver are awesome folks!), found a cheap used laptop table that I'm able to use to recline with legs up while using my computer, asked my family if anyone has extra wearable I can use to track health data and turns out my brother in law has a bunch of smart watches and is willing to send me one for just cost of shipping. Also being more proactive in using things like grocery delivery, medication delivery, etc. It's a very different mindset to proactively reduce the effort for things in my life, instead of just reacting to being overwhelmed.”
- “I tell people every time I'm able to go out (I try hard to go out once a week, that doesn't always happen, but I try, it helps me feel connected to the world) when they ask how am I doing: I'm upright. Most of the time, they agree that's a really good thing without seeing the underlying reasons that go behind actually being that. Everyone takes standing and walking for granted. It's precious and the little things in life are what make life worth living in the first place,’ - My Grandmother. Missing you greatly.”

Tiny Triumphs

- “I was able to pack up and leave on the actual day I wanted to.”
- “Made a new friend during one of my very rare walks....and a friend to walk with!”
- “Neglected to add at the beginning of the group, but my happy thing is that I got on a list with my library's accessibility services to get home delivery of library materials! There had been a really long waitlist but apparently a bunch of people dropped out so I can start in May.”
- “Went out to dinner to celebrate our 37th wedding anniversary last week.”
- “Managed to hold off on eating sugar until this group where I can hopefully stay off sugar with your support. Sugar gives me energy & joy — two things I have a hard time finding/achieving within the limits of my symptoms & restrictions.”

Resources

- ME/CFS Crash Guidebook: <https://batemanhornecenter.org/education/mecfs-guidebook/>
- “Margie Blessinger has a podcast & many programs for natural treatment of osteoporosis. It’s not geared toward people with CFS & other chronic illnesses, but you learn a lot from her.”
- Mass ME Association has a talk about living with and managing ME/CFS and hEDS (recordings shared later) <https://www.massmecfs.org/news-events/66-sunday-conversations/920-sunday-conversations-apr2025>
- Insight Timer: <https://insighttimer.com/>
- Disability resource: <https://howtogeton.wordpress.com/> has lots of good advice
- Link for Osteoporosis & Long Covid podcast: <https://podcasts.apple.com/us/podcast/happy-bones-happy-life/id1475261223?i=1000701730550>

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/invisiblyyouthgroup>
- 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](#).