Support Group: When Things Get Tough--Managing Depression with Chronic Illness

March 18, 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 kicked off the discussion by explaining that depression frequently occurs alongside chronic illness. When people are depressed, they tend to go to extreme thinking, their mood is disturbed, and their thinking can include ruminating thoughts focused on negative consequences of experiences. A disturbance within the body can occur such as lethargy, fatigue, changes in sleep and appetite. There can also be social withdrawal avoidance, isolation on what we could call a spiritual domain of life. There can be a sense of meaninglessness and purposelessness as well as sadness, hopelessness, helplessness, powerlessness, as well as inappropriate guilt.

The following discussion questions helped to guide the conversation:

1. What are you learning about depression and chronic illness?

2. What's a difficult symptom that chronic illness and depression brings?

3. What psychological or social skills or approaches help you manage or prevent depression?

4. How do you establish and maintain a sense of hope amidst illness?

Timothy's Shared Wisdom

- An important part of self-compassion is connecting to the idea that we are not alone in this reality.
- The losses and limits we experience are very real and need to be grieved.
- Timothy has found that even though there are a lot of things he can't do with his body he can connect to the things he used to enjoy by watching other people do them. He shared this to encourage participants to try and think of new ways to connect to what they enjoy while staying within illness limitations.
- It is important to create meaning and purpose out of our lives. It can be especially challenging on high symptom days. He quotes the philosopher Nietzsche, "He who has a why can bear almost any how to life."
- Anger can often be our effort to seek a sense of power against things that we don't have control over. We can shift our thinking when we get angry to realize our body is seeking power right now and ask ourselves,
    - 'How can I be powerful?'
    - 'What does being powerful look like (within limits)?'
- Sometimes hope or hopelessness can be rigid thinking. Hope can be misleading if the task is unattainable. We need to have hope in our lives but if that hope is fixed on a particular narrow outcome, it can become destructive. It is important to recognize useful hope as well as useful hopelessness such as hopelessness in things that don't work.
- Important skills can be incorporating admiration, gratitude, prioritization, radical acceptance, and reaching out socially.
- When feeling bad about ourselves for not meeting certain standards we can challenge the standards instead of challenging ourselves. For example, if we aren't excelling at something we need to recognize that it doesn't make sense for us to meet the standard because of the reality of our illness limitations.
- Unchallenged oppression is then internalized and becomes depression. It is important for us to evaluate our own behavior based on our own values and what we know about ourselves rather than externally imposed ideas about who

we should be. Reorienting to that authority within ourselves rather than from people who come at us with their own levels of ignorance.

Participants' Verbal Comments

- Participant shared that depressive episodes come when she feels more isolated. She finds it helpful to remind herself that she isn't alone in her experience and that others are experiencing it today.
- Participant shares that she finds meaning and purpose in doing advocacy work such as writing an op-ed that will be published about ME/CFS encouraging the expansion of telehealth, participating in Blue Sunday, and working on medical education.
- Participant shared her grief about not being able to have horses and property anymore. However, she was able to buy a van and put a bed in it. She uses the van to drive places and enjoy the scenery while lying down.
- Participant shared struggling with lack of variation in her days because she must conserve her energy for chores and bathing. When she has tried finding new things to do, they have made her more sick. She still tries to change her outlook despite feeling stuck.
- Participant shares missing the intense outdoor activities he engaged in and how that was a part of his identity. He is working on accepting his new reality of just paying attention to the birds, flowers, and sun.
- Participant stated that depression requires grace because our brains are going through a lot. She experienced PEM for a long time that was accompanied by depression and eventually reached out to help from people she knew had her best interests in mind and wouldn't tell her to try and think positively as a way out. She expressed that hope is the key to making it through one more day.
- Participant shared experiencing a lot of anger that causes her to have panic attacks.
- Participant shared that she had unrealistic hope by believing that medications prescribed by her doctors would cure her. When those treatments didn't meet her expectations, depression would follow. If she allows herself to experience those feelings of grief, she can then feel them shift. She is trying to find the

balance between hope and acceptance. She finds visualizations from Headspace or Calm helpful. Or she imagines herself going up a spiral staircase and going to see the same view from a different perspective.

- Participant shared that her purpose before the illness and since has been to be on a more spiritual path of developing kindness and presence along with turning her attention to something beautiful such as a bird.
- Participant explained that she experiences waxing and waning depression and shared some of her helpful tactics:
    - Saying 'that's okay,' to herself when something doesn't work out helps with acceptance.
    - Reading books with happy endings, but she must set an alarm as a reminder to stop before triggering PEM.
    - Having a safe person that she can reach out to by text.
- Participant shared the following things that help her:
    - Watching gardening videos or beach scenes at her favorite places
    - Deep breathing exercises
    - Butterfly hugs
    - Expressing gratitude toward others
    - Celebrating tiny triumphs
    - Being gentle with herself and trusting her instincts

Participants' Comments in the Chat

- "I relate to appreciating simple things, like birdsong, flowers blooming etc."
- "I have experienced acute depression separate from and before having chronic illness. For me, it has helped in self-advocacy when docs want to blame symptoms on depression than an actual illness like ME/CFS. I want to do things, have hope and look forward to things, but I have payback from the exertion or my energy doesn't allow me to. My body sets the limits, not my mind."
- "I use apps and stay curious to just learn anything that is interesting or exciting or at least new."
- "Bonsai, seeds & glowers, any recipe, bird sounds, all the mindfulness. Tapping, BREATHWORK, meditation or guided visuals."

- “Even simple things like sitting on my balcony with a blanket for 10 mins help me with mood issues.”
- “I have been able to do short bursts of art laying on my side in bed. My go to is scraper foil/scratch art.”
- “I found it helpful to list activities I could do based on my level of functioning. This is my list if you need a starting point:
    - https://postimg.cc/7bDhtFSt
    - https://postimg.cc/SnXxzkpR
- “YES! The sun is everything. And days months housebound can greatly impact this. I live next to a lake outside my window, and that saves me during most of the year when housebound. Used to have hiking and outdoors as part of my identity too.”
- “I am in my hammock on the porch, enjoying sunlight, birdsong, and a lap kitty. I must do this as much as I can before it gets too hot here.”
- “One thing that had kept me going aside from making jewelry is writing my memoir. I am doing so with the goal of publication, so I have a challenge. I need that to keep myself from sliding into depression - a place I know well. It's always good to connect with people however you can.”
- “I greatly struggle with this question as I am not spiritual, and I think being spiritual is like an easier stepping stone to finding meaning. But I found ACT (Acceptance and commitment therapy) was helpful in structuring my thoughts when finding meaning.”
- “About 6 years ago I had to come up with a purpose so I started a support group for people living with fibromyalgia ME/CFS on Facebook called Fibro Flys. I've been losing hope and purpose recently again so I've just set up some WhatsApp chats with my members.”
- “A book on ACT that helped me is *The Happiness Trap* by Russ Harris”
- “I have learned much more patience, which improves my life and relationships. I enjoy learning from online lectures, laughing with my wife, staying connected with family and friends via text.”
- “If you suffer from depression, a practical suggestion to help you control your thoughts and feelings is to create what has been called an emotional first-aid kit.

The kit, which can be adjusted as you see fit, might include the items on this page.

  - Contact information of people to call when you feel down
  - Favorite songs that are positive and upbuilding
  - Inspirational sayings and encouraging articles
  - A list of comforting and upbuilding sayings from the Bible, such as Psalm 34:18; 51:17; 94:19; Philippians 4:6, 7
  - Mementos to remind you of people who love you
  - A journal containing your positive thoughts as well as positive experiences you"

- "Celebrate EVERY small win --- our 'victories' are very different now than pre-illness. BUT anything we can accomplish -- wash 4 spoons or forks --- take the W!!! Focus on what you can do … even though that is WAY different and has been altered from what we did before ---wash a sink full of dishes. Try to redirect to see any small steps forward as making progress … maybe taking a shower every 5/6 days, when before we'd go 2 weeks between showers. If we can't paint a mural on a wall, perhaps we can sketch a quick pic."
- "It's helped me learn how to listen to my body and honor its limits. It's a painful lesson, but I don't know that I would have learned it any other way.
- "Don't have energy or mental focus to watch a 2 hour movie --- watch a 20 minute inspiring TedTalk."
- "I have learned much more patience, which improves my life and relationships. I enjoy learning from online lectures, laughing with my wife, and staying connected with family and friends via text."
- "To experience love ~ to give love and to receive love. Finding ways to love ourselves, to love things around us, beings around us (plants, cats, people, supporting/being supported in online groups …) To me, this is always my reason. Some days and some years have been just surviving. And I'm glad I've persisted. It's not fu*&ing easy. Sending care from bed."
- "I'm depressed all the time. I simply refuse to dwell on it. I keep going back to what Meredith told us forever ago about not wasting our spoons, especially on things that we can't control. So I choose to not waste my spoons on anything negative."

- “Museums have online exhibits, which can be great.”
- “Following up on Timothy's earlier comment, my new video is about a powerful source of inspiration as I seek purpose in life: Laura Hillenbrand who wrote 2 best-selling books while homebound with ME/CFS!! https://www.youtube.com/watch?v=U4-H9BA9CCY&t=98s”
- “My therapist has taught me to process in short bites. I do a visualization of putting my feelings/memories in a beautiful box to go back to later. It took practice, but it has helped me a lot.”
- “I want to give a shout out for those that get a lift or joy from creative works, there’s a ME/CFS and Long COVID Facebook group for creativity. That’s all they allow. They encourage using other groups for medical discussions, etc. It is a lovely space.”
- “There's an online support group called "Supporting Loved Ones" from Center for Chronic Illness, you can search for it on HeyPeers website https://heypeers.com/online-support-groups”
- “I have been taking things day by day, and learning to say, ‘it’s ok’ and accepting my new life is definitely something I’m working on. I need to set timers for myself though, being someone with ADHD and OCD, I will let myself carry on beyond my limit. The balancing act can be difficult sometimes.”
- “There are great guidelines that you can share with your surgeon and/or anesthesiologist. https://mecfscliniciancoalition.org/clinical-management/ scroll down to special considerations and click on recommendations for surgery and anesthesia.”
- “In the occupational search field there is a term “transferable skills”. I think that if we applied that concept to our mindset it might help. Some people find joy in creativity, others in connecting to/helping people, others to achieving a goal, etc. If we transfer our skills and orientation pre-illness to the now then perhaps we might find a more livable mental state. Perhaps not. Of course, it would have to be in a different way than previously. The biggie is using exercise for relief and enjoyment not an option for me now. I just think that sometimes we think in terms of one size fits all and it doesn’t always work.”

Tiny Triumphs

- “Said no to visitors & didn’t feel ashamed or guilty afterwards!”
- “Continued running long COVID spaces & through LC awareness day. Now being ❤️‍🩹 ✊ gentle resting.”
- “I was able to be at my child's birthday party and didn't crash. I haven't been able to celebrate their birthdays in years.”
- “I was able to drive 25 miles without my pap machine. First time I went without it in at least a decade. FYI... I wear it anytime I drive over 10-15 miles.”
- “I started using Transcendental Meditation again.”
- “Harvested my first three asparagus spears from seeds I planted three years ago.”
- “I had my quarterly follow-up with my family doctor at the end of Feb. She says she uses the BHC website I shared with her and it is helping her diagnose other patients coming in with similar symptoms!!”
- “I told my mom I couldn't help her clean the garage. She yelled at me and told me ‘You're not that disabled!!’ ... which sucked... but was really proud of myself for knowing my limit and putting up a boundary.”

Resources from the Session

- Caregiver Resources
    - Severe ME/CFS Caregiving webinar: https://youtu.be/ryVxxx3h_bM
    - BHC webpage for caregivers: https://batemanhornecenter.org/outreach/care-partners/
- Website of Anna who founded the Blue Sunday for ME https://the-slow-lane.com/

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.