

Support Group Recap

I Get Knocked Down but I Get Up Again

April 16, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
 - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is recruiting for two Long Covid studies. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.
- Latest newsletter: <https://batemanhornecenter.org/wp-content/uploads/2024/03/Winter-2024-newsletter.pdf>
- ME/CFS Awareness Event on Tuesday, May 14th, at 1 pm MDT. [Register here.](#)
 - [Submit your questions for the expert panel here.](#) Due May 8th.
 - [Submit your content for the video montage here.](#) Due May 8th.
 - [Click here for more details.](#)

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

Timothy introduced the topic by defining resilience. Resilience has a double meaning:

1. In general terms resilience refers to when people can face difficult things successfully.
2. In psychology there is “recovery” and “resilience.” Recovery is when something difficult happens to you and you can improve back to your baseline where you were psychologically. Resilience is when you have enough skills that you aren’t very affected on a psychological level when a challenge hits you. This is unlikely to be the case when facing these very difficult diseases. However, we can keep increasing our capacity to get closer to a sense of resiliency. Research has shown that the following factors contribute to resilience.

Personality/Character Factors • High intelligence • Low neuroticism (contained emotional reactivity and general emotional stability - although this can be a relatively stable trait characteristic, different therapeutic approaches can help us with this) • High extroversion

(being sociable, expressive, outgoing) • High conscientiousness (being organized, reliable, methodical) *We can't change some of the above factors but there are some that we can have influence over.*

Other Modifiable Factors (factors that are often targeted through psychotherapy & other interventions) • Psychological flexibility (the ability to persist towards goals by changing behavior in the face of competing influences) • Psychological hardiness (knowledge of one's purpose, values and goals; engagement rather than avoidance, isolation & alienation; a perception that one can influence events and outcomes; seeing problems as challenges that promote growth rather than as "calamities") • Marital stability • Social connectedness (having others in one's life who make one feel a sense of: inclusion, common belongingness, and emotional intimacy) • Economic stability • Rational thinking skills

Discussion

Timothy's Shared Wisdom

- It's important to cultivate the idea that no matter what happens I can keep adapting to figure out what I need to do for myself.
- Another component to resilience is seeing problems as challenges that promote growth and learning rather than calamities. For example, asking oneself, what is my illness teaching me? What can it teach me? What can it teach others?
- Mindfulness is one of the most robust tools that has helped Timothy in his illness journey.
- The pop song Tubthumping is where Timothy got the name of today's topic because it was an anthem for him when he first became ill. It helped him to mentally keep getting up even though he may have been stuck in bed.
- Approaching/living with others: There is a layered process when it comes to coping with people who respond to our illness in an emotionally unhealthy way. Respite is an important component for our caregivers. But beyond that stress can bring to light character and coping skill issues. Things that needed attention originally come to the forefront. If we aren't careful about labeling and differentiating that we can start to internalize and invalidate our own illness experience and even start to blame ourselves inappropriately for things. It's a layer that we want to buffer against and be aware of. In communication with this kind of person we can always see beyond the behavior to

see what the core feeling is. For example, you could say, "I can see that you are overwhelmed by this also. When you are angry with me it doesn't help me, you, or us. Can we handle this in a different way?"

- Couples therapy is a great way to help people adapt to new situations. It can work through communication issues, relational dynamics, and managing our feelings.
- Pain is self-absorbing, and not in a malevolent way like the way someone may accuse another of being self-absorbed. But rather when we are in pain with our illness our vision can shrink. It's a natural reaction. It can be helpful for us to keep recognizing that that's a process that occurs.
 - Caregivers: It can then be easier for us to forget about our caregiver's needs and limits. It's helpful to remember to be able to pull out of that.
- Anger and frustration often point to where a boundary is needed. If someone is blowing up, it's because they haven't been setting boundaries along the way in their limits. It's important to honor our own limits and to do our best to honor the limits of those around us but in a non-depressive way.
- Self-compassion is so important. A lot of us have a false subconscious belief that we're going to hate ourselves into healing from our disease. Or we are going to hate other people into changing how they respond to us.
- Take things moment by moment. So much suffering is created because we are projecting into a feared future. Or we don't trust that we'll do what we've always done which is risen to face the occasion of any stressor.
- Anger is initiatory but not transformative. It motivates us to take a different kind of action that does transform the situation or improves it.
- Some tips for improving psychological flexibility (capacity to maintain our goal but adapt the way we go about it) For example, if you love dance, find a way to enjoy it - perhaps listen to music and image the movements or watch a dance performance on YouTube. That way your still connected and have that art medium in life.
- Psychological hardiness lends itself to seeing what we are going through as growth and learning instead of catastrophe (this shouldn't be happening, it's intolerable). These illnesses do cause grief and at the same time so many people learn and grow and expand their sense of self and capacity through facing really difficult challenges. This can be done through adjusting our internal monologues and our perspectives.

- Recognizing your strengths and what you HAVE accomplished over time is excellent.
- “Instead of fighting my disease or body I started to shift my mentality to working with them and not judging that it’s wrong or shouldn’t have happened. I accept it more as a natural part of life.” A synonym for fight is hope. So, what can we hope for in our lives with our illness not despite it? Trust that you can keep doing what you can for yourself.

Participants Shared Things They do to Help Their Resiliency

- Counseling
- Mindfulness
- Smile and try to listen to loved ones and friends, even briefly. Whatever I can manage. This helps me to feel attentive and lets people in my life know that they are important to me.
- Attend BHC support groups and Lunch & Learn.
- Attend CFS/ME Friends support groups on Facebook. (See link in support group list below.)
- Mindfulness meditation and an online meditation group that meets once a week.
- I try to go to the pool once a week, when things are going well, 2x a week. When things are going poorly, I remind myself that there is always next week.
- Snuggle with my dog.
- There are times that coping comes easily and other times when I wonder, “how much more can I tolerate “. It’s all cyclical and keeps changing. On difficult times I try to remind myself that things might be better soon. On good days, I remind myself to slow down and savor the good days.
- Repeat a positive mantra, call a friend, deep breaths, search for a funny/cute reel in Instagram with puppies or babies. These won't change your situation but can help give you a few minutes reprieve or make you smile for a minute.
- I sometimes envision myself as a stone in a stream, letting the water go over, flow around... it gives a sense of peace, being in the moment...not giving up or in, just allowing the moment to be...whether pain, brain fog...it helps the healing.
- Find friends with chronic illness. Minorities connect with each other to experience validation and full understanding.
- My therapist gave a great exercise utilizing writing: left hand (or non-dominant hand) writing. Using that non dominant hand to write your gratitude’s, your positive

glimmers etc. When using the other hand, it creates more new neural pathways and can really help with depression or cycles of going around and round in your head. I hope I explained that okay. Worth trying. Using the nondominant hand also uses a different part of the brain, so you may forget how to spell even simple words and that is totally fine. The more you do it, the better and stronger those pathways become.

- Tip: Medicare gives 16 rides to doctor visits a year. Look into the benefits your health plan provides.

Participants shared suggestions for how to deal with someone's erratic / uncomfortable behavior, as it affects the resilience of living with chronic illness.

- Expanding the support system.
- Lean on friends and other family for support when possible.
- Our caretakers need more respite.
- Divide and distribute labor.
- "Support precedes movement" ~ helpful way to remind myself that if movement isn't happening inside and out it isn't anyone's fault, it means there's a lack of support. It helps me turn towards what is NEEDED and out of a blame story. (Learned from Bonnie Bainbridge Cohen.)
- Imagine I'm a plant...what does this plant need? How can I help them grow and flourish?
- Empathy and self-compassion when I can't meet a need that I or someone else has.
- Reach out in an ME support group if you need to connect with someone who understands.
- "You & me against the problem instead of against each other."
- Writing exercise or lying still and doing micromovements such as with your hand.
- Self-compassion is so important, as well as compassion for others.
- Lack of self-judgment. Kindness. Not isolating. Connecting to common humanity.
- Take things moment by moment. Try not to project into a feared future. Build that sense of peace, calmness, and capacity.
- Emotionally regulate.
- Connect with your partner through acceptance.
- Recognizing that every person in this home is going through the grief cycle and we are not all going through the same stages at the same time. Participant and her partner shared a song with each other that resonated with where they were each at emotionally.

It showed her how much he cares and how much anguish is happening as he is processing what is happening.

- When her partner comes to see her, she tries to focus on one good win for the day instead of how bad the day is.

Resources Shared During the Session

- Resilience journal (free)
 - <https://www.yoyolin.com/shop/resilience-journal-downloadable-pdf>
- Participant co-created and co-moderates a disability/chronic illness meeting (Mondays 3 pm ET) through Survivors of Incest Anonymous. It's a fellowship for those interested in recovering from the effects of abuse.
 - <https://siawso.org/wwvm-calendar/>
- Pillow writers or pillow crafters. No art or writing skills needed.
 - <https://pillowwriters.wordpress.com>
- CFS/ME Friends (meets on Zoom)
 - <https://www.facebook.com/groups/CFSMEFRIENDS>
- 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/>

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/>

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](#).