

Support Group Recap

Beyond Betrayal, Cultivating a Positive Relationship with Our Bodies

May 21, 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>
- 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 resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance nor endorsement.

Licensed clinical social worker, Timothy Weymann led this session.

Quotes:

- "You yourself, as much as anybody in the entire universe, deserve your love and affection." — Sharon Salzberg
- "To love oneself is the beginning of a lifelong romance." — Oscar Wilde
- "Self-compassion is not about comparing yourself to others; it is about accepting yourself as you are and embracing your journey." — Kristin Neff
- "To be yourself in a world that is constantly trying to make you something else is the greatest accomplishment." — Ralph Waldo Emerson

Research shows that one of the most common themes people with chronic illness experience is the feeling of betrayal by their bodies.

We have relationships with people, events, emotions, situations, and objects (like your body). Relationships are how we interact with someone or something; and how we attend to them or it. Humility can be a big challenge but also brings opportunity.

Timothy asked the group to consider the following questions:

- 1) What constitutes a healthy relationship to your body?
- 2) If you acquired illness later in life, how does your relationship with your body differ from now being chronically ill versus when you were healthy?
- 3) What are the barriers for you in regards to cultivating a positive relationship with your body?
- 4) What has helped you if you feel you have a positive relationship with your body?
 - a. What has helped you develop or cultivate that?

Sometimes we confuse guilt with empathy. Move away from guilt; if you are empathizing or connecting with your body then that's okay because you can appreciate and listen to your body. We all have a place here that will not be denied. It's important that we have a healthy level of entitlement with your body.

Relationships can be complex, it can be nuanced and back and forth. The more grateful I am for my body, the more I respect and listen to it.

Differentiating when I am being conscientious and preparing vs. hypervigilance (which comes from a trauma or fear response).

- Can we consider inconsistency to be consistent, and manage life around that knowing?
 1. Identify what won't come back (and allow yourself to grieve it).
 2. How do I connect to what I once loved in a new way?
 3. What are the new things that I am going to do, not in spite of my illness, but with my illness?

Betrayal vs. fear

- Fear my body will fail me.
 - Traumatic experience to not be able to trust your body.
- Fear of not having the resources (monetary or otherwise)

- After taking for granted that my body will always be there for whatever I needed, it has been difficult to learn that how my body feels determines what I can do. And I don't know from one day to the next what I'll be up to doing. Makes me disappointed and frustrated.
- No room for unexpected spontaneity.
- Maybe fear for some people, or experience with facing challenges and knowing the limits. Being realistic.
- The inconsistency is the most difficult for me to accept. It causes me to be fearful of making plans (not knowing if I'll be able to follow through).
- Not necessarily fear that the body is betraying but rather fear for how fragile the body has become.

Working from a risk assessment stance with ME/CFS

- Accurate risk assessment to be quite cautious is my experience too and has helped maintain a more reliable “envelope “when listened to.
- Helplessness amidst a threat. We do this with our bodies too. Limits make us do this.
- I appreciate my healthy body retrospectively and wish I appreciated it more at the time. Since being sick, I've become so hyper aware of everything within my body. It's exhausting having to notice how my body is impacted by every small thing out of my control such as the weather, the bus being late and having to wait longer than anticipated, food sensitivities etc. However, I also notice how much better I feel by the sea, on a sunny day, when I eat fresh fruits etc. So, there's good and bad.
- Taking for granted that your body will always be there for you; then it isn't.

Body image

- Really rooted to how you are doing.
- Don't beat yourself up with the changes in your body; be kind to yourself.
- Freedom with acceptance and the freedom that comes with allowing yourself to experience something that you didn't think you would do.
- Take up the space you deserve in this life.

Loss of identity

- If my body isn't how it use to be or part of what I was, then who am I?
- Who are we when we live in these changing bodies?

- Life is asking us to face our own humility. It is always there, but we take it for granted when we are healthy.
- Working out what things you can still do.
- A journey to learn a new way to feel connected to life.
- Finding small things in life that bring joy.
- Rediscover different parts of yourself and grieve past things that you thought held identity to you.
- Reinvest.
- If I am not the things that I do, then who am I? What makes us a person. We all are in change and a shift of change and chronic illness magnifies this and expedites this; so, beyond the relationship without body, what's our relationship with change? Do we meet it with control, anger, resistance? Or do we meet it with compassion, grace, acceptance?
- You are your timeless awareness. You are the one observing, the one who is aware.

1. For you, what constitutes a positive relationship with your body?

- I appreciate what good it does do me, such as send me feedback about my well being, and small things such as digestion and what mobility and energy I do have.
- My body is working in an admirable way. It is working so hard to fight this illness.
- Giving yourself grace.
- We have to show ourselves the patience, love and grace we so easily give to others.
- "My body is here to help me." Even though this is showing up in a different way.
- Listen more to your body.
- Relationships with a chronically ill body can be volatile. The more grateful I am with my body, the better my illness experience is.

2. If you acquired illness later in life, how does your relationship with your body differ from now when you are chronically ill versus when you were healthy?

- I still haven't come to grips with the weakness and shortness of breath that I experience on a daily basis. I was physically fit for years (21 years in the Army), so I am just baffled by this new reality.
- Took for granted healthy body.
- Was rough/tough/unfair to healthy body.
- Overly critical of healthy body.

3. What are the barriers for you in regard to cultivating a positive relationship with your body?

- Can be aware and mindful of the need to rest, but an attachment, stubbornness, and a quality of unkindness to yourself can result in pushing past the need to rest/break.
- Mind will ignore, minimize, push against the obvious needs of the body to keep pushing and extending.
- Barrier: giving myself compassion for myself.
- Mind is betraying my body's needs.
- Not listening actively to ourselves. So, it is with our body. Cultivating the capacity to listen to our bodies.
- Often times we don't give ourselves the same latitude that we give others. We expect more of ourselves than others.
- I was recently told that I can't hate myself into not hating myself.
- Beating yourself up is a waste of spoons. Our spoons are too valuable to use them in a negative way.
- Grief as a constant companion and it adds to the exhaustion.

4. What has helped you cultivate a positive relationship with your body?

- Somatic exercises
- EMDR
- Vagus Nerve Stimulation
- Therapy
- Mindfulness practices
- My yoga teacher always has us thank our bodies for their years of service. That helps me, as I hear her voice when I'm grieving the abilities I've lost.
- Take inventory of celebrations and grieving.
- What do I need to do? Take action, rest, write a note to doctor, etc.
- Learning to look through a different lens.
- I am partnering with my body. My body is a part of me. Being mean or talking poorly isn't going to make me feel any better. It's only going to make me feel worse.
- Years of breath and movement, meditations of many kinds, hopefulness, knowing that "this too shall pass."
- My inner core remains unshaken throughout my life. Single-mindedness.
- EFT or Tapping techniques.

- Mirror routine
 - Stare in the mirror and feel love for your body.
 - Mirror time! My therapist gave me this exercise too. Even just smiling at myself and speaking or coming up with positives were hard. It became easier to find positives - not just physical but saying thank you to my body. Thank you for small things... it helps.

Resources Shared During the Session

- Pillow crafters (art) and pillow writers (writing). No skills necessary. Very nice and friendly groups. You can participate when you're up to it or just listen. <https://pillowwriters.wordpress.com>
 - The link has dates for both groups. There's more info about pillow crafters here: <https://pillowwriters.wordpress.com/2023/01/10/pillow-crafters/> (It says Mon/Tues, but we meet on Wed.)
- ME International
- ME creatives group that MEI runs on Facebook groups
- Practicing Body Gratitude with Chronic Illness by Meredith Mehner
 - <https://youtu.be/W3TRKB1TzIQ>
- Guided Questions for Practicing Body Gratitude by Meredith Mehner
 - <https://youtu.be/Gg6j2K8OAp0>

General Resources

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](#).