

## Support Group Recap

### How Labels Construct Narrative: Constructing Illness Narratives that are Truthful and Serve Us.

June 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 July:**
  - Tuesday, July 16, at 1 pm, MT
  - Tuesday, July 30, at 1 pm, 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. He introduced the discussion by explaining that we are all narrators of our lives. We're constantly creating stories about what's going on in our day and on the broader picture. When we look at our past, we have a narrative of what happened. We also project into the future with various narratives of what we think will happen. Those can split into two different things 1) what we hope will happen, 2) what we fear will happen.

Timothy provided the following list of questions to guide the conversation:

1. Have you intentionally constructed a narrative around your illness? If so, what is your narrative?
2. What narrative do you have, or have you had that increases your pain or suffering?
3. What narrative have you created that brings you peace?
4. What narrative have you created that makes you feel connected?

5. What narrative have you created that makes you feel empowered?
6. What's a narrative are you struggling with right now?

**Timothy's shared wisdom:**

- Timothy shared that when he first became ill, he had a narrative of hopelessness. He felt that his life was over and that nothing good would ever come of it. This reaction was a natural part of grieving and adjusting to significant life changes. However, over time, he challenged that narrative and found his way out of it. Now, he has developed more positive narratives. He views his health challenges as opportunities for learning and growth, considering what these challenges do "for" him rather than "to" him. Additionally, he recognizes that his illness has connected him with people, such as those in this group, whom he would otherwise never have met.
- Timothy's narrative around loss is, "Can I lose what I never had?" Such as when he looks at life and bodies and sees how it's all impermanent; was it really his to begin with? He still grieves the loss of capabilities, but he no longer believes that he has to have them, that he is owed by them, and that his life would be unlivable without them.
- Dirty suffering vs. clean suffering.
  - Clean suffering is when we get an illness and we have grief around it. There are changes we must mourn.
  - Dirty suffering is when we have a difficult time and make it worse by the story we tell ourself about what is going on.
- Timothy's hopeful narrative is that he will keep making meaning and purpose and that he will touch into something that's meaningful to him or that he cares about.
- It's important that we make room in our lives for anger. Anger is our body's attempt towards safety and power and safety through power. It's okay to be angry because these are big changes to our lives. It's also important to not be stuck or rooted in anger as this drains our energy envelopes and leaves little room for meaning making.
- Many people with and without chronic illness have a narrative about the discrepancy between our ideal self vs our real self and reality. We are grieving an idea for how we thought things would be. There is a place for that grief and at the same time if we don't intentionally address that process, we can keep a prolonged sense of suffering because of the difference. Part of that healing is reconnecting with your continuity of being; how are we still the same?

- Related to experiences with these serious illnesses. Who am I without this ability? Who am I without this hobby that I've loved? This is an invitation for us to create a narrative about how we are an expanded self that is beyond what we used to do. We are bigger. There is more to learn and grow. There are more ways to be who we are and we are going to keep discovering that as we commit to our lives as they are.
- Dr. Rachel Naomi Remen who has been very ill with Crohn's disease says that the repository of wisdom to live well in this world resides within the sick.
- It's important that we identify the causes of certain narratives and that we appropriately externalize other people's limitations. As you are able to practice the skill of realizing when a comment or lack of understanding is about someone else's limitations and not your own, you can relieve yourself of a lot of suffering around your narrative.
- If we tell ourselves a story that the only acceptable future is to get better, we could be setting ourselves up for additional pain. But we can have a more expansive hope for the future such as being better at managing the illness or getting better means becoming wiser because of the illness experience, or it means building a strong sense of self-worth.
- If someone is struggling with us being ill and they are our caretaker, it's helpful to remember that they are struggling with life because this is part of life. We can also flip the narrative to being an invitation for them to grow.
  - Be aware of the burden narrative because it is destructive. We aren't choosing to be sick, and we are experiencing the pain of illness too.
- Poet David White said, "Give up all worlds but the ones to which you belong."
  - It's important to realize that the constructed narrative of how things "should have been" are just ideas. They were never real to begin with. Recognizing this can loosen the grip of that intense pain that can come from focusing on the discrepancy between the ideal world and self vs the actual world and self.
- One day your story will be someone else's survival guide.
- Andrew Solomon said, "After you forge meaning you need to incorporate that meaning into a new identity. You need to take the traumas and make them part of who you've come to be, and you need to fold the worst events of your life into a narrative of triumph. Evincing a better self in response to the things that have caused you hurt."
  - Remember that your story is valuable, and you are valuable.

### **Participant Comments:**

- Recently been reminded of what she had before becoming ill. “It’s been very painful to think about. I know I must create a new narrative but sometimes the loss dominates my thinking.”
- A narrative that brings peace is, “I don’t have to work in a terrible job anymore.” A narrative that feels empowering, “I have time to do things like spend more time making jewelry.”
- Realized my narrative since becoming ill in 2007 is that “If I live perfectly, physically, spiritually, lost all the weight, said all my prayers that I would be well.” With the help of therapists I realized that the illness isn’t going away and a new narrative needs to be constructed.”
- Feelings of being a burden on caregiver, angry that she has to deal with Long COVID on top of other illnesses and frustrated that she can’t create art.
- Educating others and immersing herself in helping others and being aware of their experiences has helped her to create a narrative of empowerment.
- Realized during this session that she has brought forward a narrative of invisibility. Expressed realizing that she needs to let go of other people not understanding. She isn’t bad because of the way someone responds to her.
- Doesn’t want her life to be a sad story but needs to have a realistic narrative.
- At a time when she was feeling like a burden to her husband she remembered going backpacking and helping to carry the pack for a friend who was injured. This memory helped her to flip the narrative from being a burden because her husband lovingly chooses to care for her.
- Other cultures allow the reality of life to be displayed and accepted.
- We need to allow ourselves to construct narratives with the horror we have experienced and at the same time hold on to some thread of our story which makes our story one of billions of human narratives on this planet that are important.
- It’s not about whether being sick is fair or unfair. A healthy narrative is for ourselves. Trying to find a narrative for myself that has some meaning and shape.
- Changed my narrative from, “bad things happen to me,” to, “I am a child of God.”
- “My original narrative around my illness was that I caused it by overexerting and not taking care of myself. Now I see that it is important to reflect upon your behaviors, but I was causing myself a whole lot of unnecessary stress by blaming myself.”

- Mine was “if I live perfectly, I would eventually heal.”
- “I’m not getting better, or in fact, I keep getting worse no matter how much I follow all the rules. So, it’s hopeless to expect more. But I accept what I am now.”
- “My narrative these days is (I have FM) my main job and goal is to treat my pain, so that I can think and perhaps have some distractions.”
- “One narrative is that this illness was inevitable as a result of childhood trauma. Given how common ACEs are, I do not give such weight to that narrative as I feel it is too close to 'victim blaming' and gender stereotyping.”
- “A fellow disabled friend (who has been unwell for more than a decade -- my long COVID started last year) was actually just telling me that thinking more about the stories I tell myself about myself, and that thinking about creating ways to tell positive stories about what's happening in my life (not necessarily about my illness, but about my life) will be very important.”
- “I can’t do what I love as what I love hurts me (excitement, socializing, hobbies, etc. will cause crashes for me). So my life is full of things I don’t want.”
- “I try not to have a self-image that is about a ‘social self.’ I try to have a subjective self only, Because I live in a parallel world so why thrust myself (in my mind's eye) into the social realm which is mostly comparative.”
- “I do have positive narratives too like this has made me a better person. More open to really listening to people, more open to knowing we control nothing in this life except our moods and behaviors. I believe this illness has opened me to become a much stronger person and it has taught me a lot of great emotional lessons.”
- “I woke up feeling sad today, thinking about the negative narrative I’ve had since Retirement/Disability. It’s feeling that I no longer have a purpose... Still working on finding a new one.”
- “I got sick when I was 18. I am now 53 and have never had a normal adult life. Grieving all of those losses feels like a never-ending process. I try to balance it by being grateful for all I do have, but the struggle between the two continues.”
- “Like all grief experiences, we have to remember we can take each step and each day at a time.”
- “I keep meaning to try a moon ritual just to help connect with waxing and waning energy, release and gather 'energy.' These links offer some beginning ideas to develop a personal practice: <https://www.spiritualityhealth.com/the-spiritual-meaning-of-moon->

phases and <https://www.spiritualityhealth.com/columns/pathfinding-yoga-andmindfulness-for-a-full-life>"

- "I'm trying to get rid of the narrative that I can do stuff ...the cost is just my suffering and that's ok as long as others are happy. .... new narrative...it's good/ok to live in my energy envelope (that would be a challenge to achieve, but it would be helpful if I thought that it was valid way to live."

### Quotes Shared

- *The Comfort Book* by Matt Haig: "Being, not doing. You don't need to exhaust yourself trying to find your own value. You are not an iPhone needing an upgrade. Your value is not a condition of productivity or exercise or body shape or something you lose via inactivity. Value is not a plate that needs to be continually spun. The value is there. It is intrinsic, innate. It is in the "being" not the "doing."
- David Foster Wallace commencement speech, "This is Water." It's only semi-related, because it's not about disability, but it is about how we choose narratives and stories that we tell ourselves. <https://www.youtube.com/watch?v=DCbGM4mqEVw>

### Resource Shared During the Session

- <https://www.goodreads.com/book/show/59867868-my-body-is-not-a-prayer-request>

### 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 2<sup>nd</sup> and 3<sup>rd</sup> 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](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](mailto: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](mailto: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](#).