

## Support Group Recap

### What does it all mean? Creating purpose out of the chronic illness experience.

April 9, 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 8<sup>th</sup>.
  - [Submit your content for the video montage here.](#) Due May 8<sup>th</sup>.
  - [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 paraphrasing philosopher Friedrich Nietzsche in that those who have some kind of purpose behind their lives can bear whatever the conditions that life brings to them. This philosophy was amplified by the teachings psychiatrist Dr. Victor Frankel who survived the holocaust in the early twentieth century.

#### Timothy's Shared Wisdom

- Having meaning and purpose has been linked to improved mental health. It also helps people to be resilient.
- For some people meaning may be religious but for those who are agnostic or atheist it means something else. Whether we are religious or not religious, we are all involved in the mystery of life and death and we all have to come to terms with that.
- Making meaning and purpose can include grieving the losses and then reinvesting into our new self.
- Mindfulness has been a helpful tool for Timothy to cope with chronic illness.
- Art is a powerful medium and is helpful for processing trauma in a different way.

- A journaling or reflective process can be helpful when facing your illness. He recommends having three categories:
  - What do I need to say goodbye to that will not be returning?
    - i.e. dancing
  - What can I reclaim in new ways?
    - i.e. watch dancing
  - What will I create as new to me?
- He challenges the idea of we are what we “do.” The reality is that all humans live in dynamic aging bodies that have changing abilities throughout our lives. By definition we are not able to “do” everything forever.
- Questions embedded into living with a chronic illness:
  - How do I reconnect to loving my life?
  - How do we admire our life even as we’re ill that cultivates that kind of love?
  - Will you love me and accept me without condition?
- It can be helpful to reframe life as a collection of experiences rather than a checklist of achievements. “If I’m stuck in bed, that’s an experience. By having a more open idea about what life can be about can make it easier.”
- Author Marcel Proust said the real voyage of discovery consists not in seeking new landscapes, but in having new eyes. This illness experience can open our eyes to change our outlook and possibly grow in how we see ourselves and other people in life.
- We/you are the model of resiliency and courage for the people we come into contact with. We role model the important commitment to life and thus are serving that purpose.
- “Life is a garden not a road; we enter and exit at the same gates, what matters most is what we notice.”

### **Participant Comments about the Challenges of Finding Meaning**

- “I started my chronic illness journey when I was a teenager. I’m now almost 40. It’s been a hard and lonely road and one that people don’t understand. It’s been a struggle to find purpose and reason. I’ve learned that it’s definitely important to find things that make you happy and appreciative, every day.”
- “What is really hard is learning to find meaning and acceptance within yourself when others around you do understand or are judgmental of your condition.”

- “Who am I now if I am not “that” anymore. We are tied into what we did/the doing part.”
- What energy did I bring to the world?
- Struggle with the battle between changing and adapting purpose and completely recreating it.
- What can you do when it takes all your energy just to survive?
- If I am not what I do, then who am I?

### **Participant Comments about Reclaiming Meaning**

- Participant’s therapist suggested she write a goodbye letter to the person she was before becoming ill and to make note of things she is still grateful for and include good memories. Then the following session they would work on reinventing her new self as someone living with limitations but focusing on what she can do.
- Used to take long walks in the forest which gave her a lot of meaning and a useful coping mechanism. Now that she can’t do that anymore she uses her voice as a poet to speak out for people who have a chronic illness.
- Finding something that interests her that she didn’t have time for before is helpful to occupy her mind and get excited. She is now learning about physics.
- Participant wanted to get a master’s degree but couldn’t due to illness and instead became certified as a genealogist because she could take as long as she needed on the coursework and research.
- Misses time shared with friends that included cynical humor and so has now picked up the hobby of “snarky embroidery.” Kits can be found on Etsy. The rage that she experiences over the life changes is poured into doing embroidery and then shared as gifts. In this way she is still showing up as her authentic self with friends.
- Found dancing organization called the Silver Swans which is based out of the United Kingdom. They have teachers stationed throughout the country who do ballet with just the arms. It has taken a lot of searching for her to find the books (listed under session resources) and the things that work in her life. You have to look for little holes of energy to research something.
- Identity was wrapped up in her career in the healthcare field. After becoming too sick to work in her career, she now finds meaning in advocacy. With help she submitted an op-ed to her local paper about living with ME/CFS.
- Participant adapted his love for camping into living in an RV.

- A counselor helped a participant shift from a “doing” mindset to a “being” mindset by giving her a list of words (like peace, nature, love) that she could choose from to try and live life by with a “being” mindset. For example, nature is one of her selected words and it means that she can sit outside and watch nature without “doing” anything to get her purpose out of nature.
- Finding meaning feels like pressure for one more thing she isn’t getting right when it’s all she can do to keep up with her daily life. It’s relaxing when she recognizes that it may not be her responsibility to define her purpose but rather be quiet and still and find the invitation of this moment.
- On the anniversary date of her illness each year she takes the opportunity to share with her adult children aspects of her pre-illness life to show them parts of who she is.
- “We have to reshape how we see ourselves - but our CORE -- our heart, our kindness, our sense of loyalty, our sense of humor, our spirit STILL matters! Trying to find something that brings you a moment of happiness everyday --- picturing your family, getting a hug, listening to your favorite song, watching a funny reel on Instagram, or a reel with babies or puppies -- always leads to a smile! Reading a line of your favorite poem, meditating for a few moments, standing in the sunshine for 2 minutes, repeating a positive mantra - I'm here, I'm important, my point of view matters. Celebrate the small victories -- I took a shower today!!!!”
- “Surround yourself with others that can celebrate your small victories and understand the moments that we are not as available as we would like to be.”
- “Finding new ways to do things... Could not accompany my friend in person on her fabulous eclipse adventure at a zoo yesterday, she FaceTimed me in to for the total eclipse experience with the zoo residents.”
- “I was a huge planner and doer. I have stopped making daily plans because not completing my plans gave me huge anxiety. This has helped me.”
- “I’ve started art journaling, and I feel like it's letting me reconnect with my body again (because my brain, eyes, and hand have to work together to make art) as well as giving me an outlet and a sense of purpose. Making art lets me feel like me again for a moment.”
- I love wisdoms of Dr Seuss.  
 “You have brains in your head. You have feet in your shoes. You can steer yourself any direction you choose. You’re on your own. And you know what you know. And YOU are the one who’ll decide where to go...”

Dr. Seuss

“Think and wonder, wonder and think.”

Dr. Seuss

“Humor has a tremendous place in this sordid world. It’s more than just a matter of laughing. If you can see things out of whack, then you can see how things can be in whack.”

Dr. Seuss

“I have heard there are troubles of more than one kind. Some come from ahead and some come from behind. But I’ve bought a big bat. I’m all ready you see. Now my troubles are going to have troubles with me!”

Dr. Seuss

“It doesn’t matter what it is. What matters is what it will become.”

Dr. Seuss

“I am what I am, what a great thing to be.”

Dr. Seuss

### **Recommendations and Resources Shared During the Session**

- Educational conference
  - Day 1 <https://youtu.be/2M2b63pEZ2g>
  - Day 2 <https://youtu.be/7PbNDravVmM>
- *The Wild Edge of Sorrow* by Francis Weller
- *The Alchemy of Illness* by Kat Duff
- Snarky Embroidery (Etsy)
- The Silver Swans (out of the UK)
- *Bittersweet* by Susan Cain
- *American Nomads* by Richard Grant.
- *God’s Middle Finger* by Richard Grant:  
about his experience in the lawless parts of the Sierra Madre Mountain

- “Something I find helps when days and weeks might blend into each other is to pay attention to seasons and do something to stay present and bring meaning to each for myself”  
Tips and ideas here: <https://www.mindful.org/why-rituals-matter-and-how-to-create-your-own/> and <https://experiencelife.lifetime.life/article/five-elements-for-five-seasons/>
- The following are the words the participant’s therapist gave her to select from in the process of changing her mindset from “doing” to “being:”  
Understanding | Strength | Serenity | Self-respect | Self-control | Love | Laughter | Rituals | Quiet | Pleasure | Play | Peace | Passion | Partnership | Openness | Nature | Happiness | Loyalty | Kindness | Joy | Humor | Hope | Home | Fun | Encouragement | Calm | Freedom | Fairness | Creativity | Courage | Attention | Adventure | Support | Patience | Order | Pride | Honesty | Respect | Sexuality | Excellence | Dignity | Trust | Learning | Intellect | Service | Safety | Accomplishment | Contribution | Rules | Family | Integrity | Planning | Sensuality | Honor | Equanimity | Grace | Enlightenment | Compassion | Vitality | Discovery | Security | Friendship | Truth | Relationship | Dependability | Faithfulness | Consistency | Appreciation | Feelings | Gratitude | Empathy | Justice | Reliable | Health | Self-expression | Connection | Action | Parenting | Challenge | Growth | Independence | Spirituality | Risk | Surrender | Winning | Persuasion | Beauty | Inspiration | Imagination | Wealth | Change | Community | Sacredness | Nurture | Work | Intuition | Spontaneity | Leadership | Tradition | Mastery | Belief | Power | Inner strength | Control | Invention | Admiration | Wholeness | Structure

### Resources to Share with Medical Providers

- Mayo Clinic Review for Clinicians: [https://www.mayoclinicproceedings.org/article/S0025-6196\(23\)00402-0/fulltexthttps://www.mayoclinicproceedings.org/article/S0025-6196\(23\)00402-0/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltexthttps://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext)
- Resources for PTs and OTs: <https://batemanhornecenter.org/providers/mecfs/diagnosing-managing/rehab-professionals/>
- Mast cell related interactions: <https://tmsforacure.org/wp-content/uploads/2021-TMS-ER-Protocol.pdf>
- Long COVID & Post-Viral Syndromes ECHO repository: <https://batemanhornecenter.org/providers/long-covid/project-echo/#long-covid-post-viral>

## 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/>

## 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**. We focus on monthly topics and have 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](#).