

## Support Group Recap: Grief - Reinvesting In Our Lives

July 30, 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.

*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 one framing for grief is that it is loss with no place to go.

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

- 1) What matters to me at this point in my life and illness journey? In a broader sense, what is my illness teaching me matters in my life and in a deeper sense, in life in general?
- 2) What have I lost due to illness and what did it represent to me? (For example, perhaps you can no longer snorkel in the ocean due to your illness, but that activity represented adventure to you. What's the deeper value your cherished ability or activity represented)? [Please see the attached values list linked here.](#)
- 3) What values do I want to invest in and strengthen in my life as I face my illness challenges?

### Timothy's shared wisdom:

- An example of reinvesting is someone who enjoys snorkeling but can't anymore due to illness limitation. If we go deeper and identify the value that underlies that activity, we can possibly pick a different activity that addresses the same value. Snorkeling may represent adventure and discovery so finding something within illness limitations that represents adventure and discovery may be a way to help with that need.
- If you are new to your illness or health status, reinvesting might not be appropriate at this time. It is important to work through the disorientation.

- Reconnecting to self and to your key values can help you. It's also helpful to take a broader view of how to live your values. For example, if your value is caring perhaps now is the time to care about yourself.
- Part of coping with a chronic health problem is expanding the definition of personal values and reframing them a little.
- "Your wants are small, make them larger" – How can I make things more inclusive or accessible as a person with limits?
- Dealing with isolation – making friends online can provide a sense of connection and even adventure and travel.
- The research on happiness shows that people are the happiest when they lose themselves in doing something they love. Part of what we are grieving is perhaps being separated from something that we loved. But being able to find different ways to connect to it and focus on being in the present rather than the destination can be helpful.
- Marcel Proust taught that the real voyage of discovery consists not in seeking new landscapes, but in having new eyes. Can we look at our illness experience in a different way and can that take us to new heights and new places to help us move forward with things as they are.

### **Participant Comments:**

- Held on to what she had to say from the last support group, "I'm here, I matter, I'm not invisible. It feels good to say that out loud and remind myself of those things."
- Values inclusion. Seeing disabled people more broadly represented and considered is helpful and encouraging, i.e. "Stand for the national anthem if you are *able*" at Olympic events. Are people of color being represented enough in these spaces? Notice who is missing and celebrate inclusion.
- Losing a previous life and version of self is so difficult. "My world is shrinking. I want to go do things, but I'm unable. I am an adventurer at heart, but no longer have the energy to participate. Reinvesting is hard while I mourn what I have lost."
- Even with continued illness and suffering there is a way to grow with it.
- Learning that there are two sides of the same coin – deep grief but joy in what *can* be done.
- Vicarious joy through sharing things she would like to do with loved ones so they can attend and then tell her about it. Imagination and creating experiences where you can is

a good idea, but there's still anger about not being able to do the real things. Emotions can help facilitate the journey and become an integral part of the journey.

- Grieving the loss of joy in movement such as running, cycling, and hiking while finding other pathways such as caring for house plants.
- Find the essence of who you are and how to express it in other ways.
- "Tiny joy" – just a little bit of joy every day.
- Practice to find your values. Reframing expectations of yourself – very humbling, sometimes angering, but there is a lot that can still be done.
- Shrinking of social circle. Feeling invisible in the new, smaller social world. Making new friends feels impossible.
- I don't have the energy to do things. The process is the fun part, not the outcome. Am I enjoying learning and growing? Fall in love with something in a new way.
- Thank you to Timothy for the key for what it means to create the "next life." Find something you consider precious that you can do given your current circumstances.
- We must continually re-examine what matters to us --- what do we want to use our limited energy on? Re-prioritizing what we want to do when we have some "functioning" time.
- Micro moments, cultivate peace, and find the new "normal".
- Share empathy with yourself as freely as you share with others.

## Resource Shared During the Session

- Join Solve Together to learn about new studies, some of which are surveys that can be done from home. <https://solvecfs.org/research/solve-together>
- Jarred Younger is working on having his studies doable from home. <https://sites.uab.edu/younger/>
- Personal values card sort: [https://www.guilford.com/add/miller11\\_old/pers\\_val.pdf?t=1](https://www.guilford.com/add/miller11_old/pers_val.pdf?t=1)

## 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 (meets on Zoom twice a week)
  - <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](#).