Peer Perspectives & Connections Recap: Body of Water; Performance and Conversation with Sara Nesson

June 19, 2025

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
    - https://batemanhornecenter.org/outreach/newsletter/
- Actively Recruiting Clinical Trials: Bateman Horne Center Research

Peer Perspectives & Connections topics are selected by the lived-experience presenter. Comments and questions from participants do not necessarily reflect BHC guidance or endorsement.

Summary

Sara gave a beautiful encore performance of her solo show Body of Water, a short monologue that follows her journey as a landlocked distance swimmer struggling to find the way home. Following Sara's performance, participants had the opportunity to talk about their connections to water and the natural world, grief, loss, and resilience.

If you missed the event, you can learn more about **Body of Water**, stay tuned to upcoming performances, or join Sara's email list on her website. You can also reach out to Sara if you would like to host an online event with your community.

Sara Nesson is an artist, writer, and performer living with ME/CFS. Besides touring **Body of Water**, she is also directing a dance film featuring twenty people living with ME/CFS and Long COVID.

If you are curious about the poet that Sara mentioned during the conversation at the event, Janavi Held, and might like to buy her book, *Whispers from Her Deathbed*, click here. You'll also find the Hindu River myth Sara shared in the foreword of the book.

Comments from the Chat

- Get to know you question: “What are some little things worth smiling about?”
- Wow - I feel so blessed to be a part of this. TY
- That was lovely - joy and loss. Thank you. A fellow kayaker.
- Your work always moves me so deeply.
- This was so powerful, so honest and true - simply wonderful 🌷

  You are such a gifted storyteller. It is so hard to have to give up all that.

  So very, very beautiful! You’re amazing…it was poetry and flow and soul…

  What a gorgeous story. Beautiful poetry and deep wisdom.

  Thank you for such a beautiful, moving, and eloquent piece

  I too, grieve. I too hope that one day I realize that I am the river.
- Thank you for sharing your stories - very powerful. Also good to see you!
- It felt so visceral, I could really see and feel the emotion
- It made me cry twice. I felt it to my heart, to my own river.
- What a story exemplifying our stories of loss and grief and finding us anew. Sometimes having help is so demanding.
- I really enjoyed this last year. I’m so glad we got to experience this again! I asked my husband and kids to join me this time. Thanks!
- I'm finding learning about your process very interesting. I'm writing a memoir that includes my illness experience, and you and your process are giving me some good ideas.
- That was so beautiful. I used to white water kayak and race as a teenager. I miss my horses and the outdoors so much. I’m a few years into Long COVID as a nurse. It’s heartbreaking. I’m turning 50 and my life is totally on hold. Thank you.
- I have suffered from ME/CFS since 2009. When I first got sick, my son wrote me a note that said, "You're still that same, exciting free spirit...you're just stuck in a body that can't keep up!"
- We are still all of that—we are still what we used to be capable of. Now we are something new, learning how to modify, discovering new interests, writing poetry.
- Yes, please bring back the Mishkan piece. It's so beautiful!
- Loved the "ticking time bomb" description in your piece today!
- "When I'm doing a little better, I still think I can do more." I can SO relate to this.
- Water person here!

- Mermaid here!
- What about floating in the water? Like water deprivation tanks? Could that be a compromise? That's what I did at the pool today. Just floated on a noodle. I used to be a big swimmer, but that's all I could do—and couldn't a year ago—so progress!
- BHC has become my haven in the storms of this illness and a guide through the wilderness of Long COVID. Thank you for all that you are doing for us.
- I don't seem to have enough energy to be very happy these days. The closest I get is content, sometimes.
- I'm not a water person, but a dancer. On a good day, I can do a moment or two of dance or just move my arms or hands. I love water—paddleboarding, yoga. I miss that. Going down to the river every weekend with my family. I feel so guilty my partner misses out because he won't go without me.
- I have made trade-offs for new parts of my life. I didn't choose this illness, but I have chosen to control what I can.
- In my former life I was a skydiver, climber, medical professional, therapist, vocalist, etc. I am still all those things—I just don't wear all those hats all the time.
- Go with the flow rather than against it—literally. Even if kayaking isn't accessible, this applies to life.
- "I am everything I love" – beautiful.
- Summer is so hard for water people—knowing everyone is out and being stuck indoors.
- Thank you. You are a treasure. Hang in there. We got this.
- Is there a way to get a copy of that poem? It was so beautiful and meaningful. Thank you, Sara.
- Very inspirational session. Thank you to everyone who shared their voices.
- That sounds wonderful. I wish Substack had audio—reading is too much energy.

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 Bay Area Support Group
    - https://cfsbayarea.groups.io/g/Main
- 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.