

Support Group Recap: Attending to Loneliness

December 10, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
 - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC is co-hosting with Solve M.E. a free Severe ME Webinar Series
 - Register here: <https://bit.ly/3Xa4IyW>
 - Visit the playlist here: https://studio.youtube.com/playlist/PL-OZ_5Cqdc32kbu_2mKPi73TZDOQhDuab/
- BHC Research is recruiting for clinical trials. 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 or endorsement.

Timothy introduced the topic by saying that loneliness and connection is a very important topic for all of us with chronic illness. Loneliness can have layers. One layer is society experiencing loneliness in general. On top of that is the isolation that comes with being home or bedbound. A deeper cut can be isolated yet with people in the sense of being different. Further loneliness can come from a psychological perspective where we make ourselves out to be uniquely different in a negative way.

Discussion Questions

1. What makes you lonely in terms of being chronically ill?
2. How do you manage loneliness?
3. How do you connect to others as an ill person? How do you reduce your isolation?
4. What has helped you attend to your loneliness in a meaningful way?
5. What are you learning about relationships as you navigate them as someone with chronic illness?

Timothy's shared wisdom

- As people living with chronic illness, we have to become masters at communication in order to bridge the gaps of loneliness, difference and isolation. We can reach out to someone letting them know we are lonely and ask them to listen to us for 10 minutes. Perhaps experimenting with more direct communication can bring us more of what we need.
- When we are suffering exponentially or extensively, it's often because we are being triggered by something in our past and chronic illness can push those buttons.
- Jane Fonda the famous actor and fitness guru shared that she learned in her life how important it is to literally say to someone, "I want to be your friend."
- Many people with these illnesses are single and struggle with the lack of physical touch. Timothy finds that getting massages can help mitigate this challenge.
- "Your **task** is **not** to seek for **love**, but merely to seek and find all the barriers within yourself that you have built against it." - Rumi

Participant's verbal comments

- Participant expressed the hardest part is getting sick in her 20's and being misunderstood by family members. She learned to appreciate her own presence and speak up for herself. She has given the illness a name and sees "her" as a good friend teaching the participant how to speak up and set boundaries.
- Participant shared that she has always liked her time alone but after becoming ill it has become hard because it's not her choice anymore. She finds it helpful to talk to her body parts. She learned from an article that we are never alone because we have ourselves and we can whisper comfort to ourselves.
- Participant shared that she is helped by the BHC resource, "[Chronic Illness, What I Want You to Know.](#)" She posts it on the fridge so that people who come to her house can see it.
- Participant feels invisible to family and friends. She let go of people who aren't reliable. Her friends are creative and don't understand the massive amount of pacing required. She is finding that doing parts work (Internal Family Systems) with a therapist is helpful at addressing her feelings of invisibility.
- Participant feels lonelier when she is with other people because her experience is so different than her peers. She finds that acknowledging and naming the

emotion to herself can take some of the power out of it. It helps to develop friendships with others who have ME/CFS.

- Participant expresses his isolation through vulnerability. His close friends are scattered around the country and he reached out to one he lost touch with. Participant received a very satisfying and supportive response from his friend. This participant has launched a vlog about his experience with Long COVID.
- Participant shared how she developed friendships by meeting people in support groups and communicating with them through text and Zoom. She also plays the Insight Timer live yoga classes so she can feel like she is in a class even though she can't do the yoga.
- Participant shared that he set the terms with his friends and asked them to come over and sit with him and hold his hand. This resulted in a profound connection with the friends willing to do that. He finds that Internal Family Systems work helps him in his social connections. He further explains his experience here:

- *“Several group members requested my thoughts written down regarding my experience of dealing with loneliness.” Here goes:*

Through my work with a therapist practicing internal family systems work, called IFS, I learned that the way I have connected socially in my life with most people was as a performance of roles. These roles included that of the fixer, the rescuer, the critic, the analyst, the people pleaser, the smart one, the caretaker, the comedian, the entertainer, the productive one, the achiever, etc. So, I started to learn that much of the way I communicated with others came out of fulfilling these roles, often originating in my childhood and adolescence, rather than from an authentic and core self. Consequently, these social roles gave me less opportunity to feel deeply socially nourished and supported as I interacted with others. As I learned to be more vulnerable and genuine as I have shared with others, I have begun to feel companioned and supported in my deep and true emotional needs. I have been more myself rather than just performing in a role. This has helped me feel less lonely and more nourished and loved by others.

Another thought - as someone in our group today shared, setting boundaries and expectations with others has been very helpful to me. When I have not had enough energy to engage in phone calls or even the energy to text or email others, I have asked my friends to just sit with me. To just sit beside me and hold my hand or

touch my arm. They would do this for up to an hour at a time on some days. This gave me a profound sense of being companioned and not alone. I felt in a deep way that I was no longer lonely if people would just be with me, sharing their presence with me in a close way with simple touch. It has made such a difference.

Participant's comments from the chat

- "I set up Fibro Flys a support group for people living with fibromyalgia and ME/CFS. We have a Facebook group and page. We are based in the UK and meet up in person twice a month."
- "This [Fibro Flys] has helped me with my loneliness and I regularly message some members. I've also recently joined the Finch app, and some other members of Fibro Flys have joined so we've also set up a WhatsApp group where we can chat."
- "I have made some online friends this year and am surprised at how nice that is. This support group was my first step. It's great to meet others facing the same challenges."
- "I'd say these support groups have been a great way to help with loneliness. I don't wish ME on anyone, but it's been nice to connect with others going through a similar experience."
- "I suddenly get soul-crushing DEEP loneliness during bad days or when my nervous system has a string of other odd symptoms. It's sort of like I interpret a type of nervous system dysfunction as isolation and loneliness. Seems to be helped by singing, music, or talking. Something about using the vocal cords, can literally be solo with myself just talking out loud. Anyone else noticed this or have this pattern?"
- "I have been accepting what is happening to me right now."
- "I also love following the LC influencers!!"
- "Sometimes it's helpful to me to go deep into the loneliness or whatever 'negative' emotion I'm feeling instead of running away from it. Then, usually, I come to some realization or other place that I couldn't have if I'd kept running from it."
- "I have learned that some of my friends and family would like to talk but will not initiate a call. Some have said they do not want to bother me if I am having a

bad day and just decide to wait for me to reach out when ready. So I have learned to call them.”

- “There are also “body doubling” apps or YouTube channels: live or recorded where you have ‘company’ for you to do something while they do something remotely.”
- “Touch techniques that help if you can list in the resource email - Polyvagal theory might help. Weighted blankets. Deep pressure. These help with trauma dysregulation, too. Cold water on face. — I also got better with the desperation for touch when I got a better handle on my severe crashes, the effort-crash cycling that happens with Post Exertional Malaise / PESE”

Resources from the session

- The Long COVID & Chronic Illness Resilience Group
- [Chronic Illness: What I Want You to Know](#)
- [Long Covid Musings](#) is a vlog created by an individual living with Long COVID.
- The following is a list of terms to use when searching online for supportive resources. When searching on Google it is recommended to include “near me” within the search.
 - home/mobile: labs; phlebotomy; blood draw
 - home/mobile infusion services
 - home/mobile nurse, dentist, teeth cleaning, eye exam, ophthalmologist
 - virtual eye exam
 - virtual nurse, immediate care, doctor
- Timothy Weymann, L.C.S.W.
Counseling Services for Arizona, Utah
Website : <https://www.timothyweymann.com/>
Phone: (801) 707-8723
Fax: (801) 880-7677
Email: timothy.weymann@counselingmail.com

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](#).