Support Group: Love Relationships and Illness

May 20, 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

The following resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance or endorsement.

Timothy Weymann, LCSW introduced the topic by mentioning that relationships are the last great frontier-everyone is trying to figure them out. It is normal that people struggle in relationships, and it is also the number one reason people seek counseling services. Chronic illness can significantly affect the dynamic of a relationship.

Guiding Questions

1. How does chronic illness affect emotional intimacy in your life?

2. How does chronic illness impact physical intimacy in your life?

3. How do you attend to the effects chronic illness has on your marriage/partnership?

4. For those who are single, what barriers and solutions have you navigated while dating as chronically ill?

5. What are the skills you want to develop to help your love life in the context of disease?

Timothy's Shared Wisdom

- It is important for us to ask for our needs and wants to be fulfilled. Professional massage can be a way to incorporate physical touch into our lives.

- Relationships are what two people decide them to be. Holding on to a particular standard or idea can block us from relationships. Rather, we can be flexible to how a relationship proceeds.

- Everyone brings positive and negative elements to a relationship. Sometimes we get over focused on what our illness brings in a negative way or lose sight of how the other person has baggage or issues. Maintaining a balance in our awareness can help reduce the sense of being in a deficit with what we bring to a relationship.

- Being resilient means being strong in the face of challenges. Research shows that resilient people have a learning orientation towards life. Conflicts in relationships, disappointments, and simply being in a relationship are all invitations to grow and learn. Maintaining that mentality can help to keep us going and keep us strong.

- When we face something stressful, issues that probably needed our attention already become prominent. People with chronic illnesses tend to blame themselves when issues come up but it’s an important reminder that some of the relationship issues were already likely there before.

- Adult relationships can be a performative stage in which we reenact childhood wounds, and we can tend to enter into dynamics that are old but somehow new. We can heal those wounds when we show up differently and give ourselves what we needed then.

- We can personalize rejection into thinking it is about us rather than realizing that the relationship didn’t work out because we aren’t a good match and we need someone who can understand and accept the elements of living with a chronic illness. To help with rejection when the illness plays a part, we can manage the resulting feelings by making lists of what the illness does for us and what we learn from it. When we can't leave our bed, we can work on our emotional intelligence by trying to understand why and how people feel.

Participant Verbal Comments

- Participant shared that her last relationship was with a person from the chronic illness community. She found couples counseling helpful for both the relationship and for decoupling given that they share the same chronic illness spaces.

- Participant share that she appreciates seeing plenty of older women "doing the single life" in a really nice way.

- Participant shared that she misses physical affection because her husband isn't affectionate but that she finds good emotional relationships online.

- Participant shared that he is in a romantic relationship with someone who is also ill and lives far way. He doesn't know if either one of them will be well enough to travel so they can meet yet it is a blessing to be in a relationship with someone who understands the illness so well. He has a sensitive nervous system and being part of a 12-step program helps him to be more loving and honest.

- Participant shared that being ill has allowed her to set more boundaries, tune in to her sensitive side, and be selective about the people she allows into her life. She finds herself being more authentic when meeting people and doesn't believe that chronic illness should lead to a belief of being less deserving of love or affection.

- Participant has learned to be more loving with herself and focuses that love inward. Her emotional and sensitive parts are the superpowers that make up who she is. She has let go of people pleasing and trying to make others see how she is feeling.
- Participant shared that her illness limits traditional physical intimacy with her husband. Instead, they focus on being very loving with each other, sharing long

hugs, kisses, and holding hands while watching TV.

- Participant shared the following adaptations that he and his wife have made:
    - When he became too ill to help with the household labor he took over financial management tasks from his wife.
    - They developed rituals of doing the New York Times spelling bee together and watching comedies on TV in the evening.

Participant Comments from the Chat

- “We always have to remember in an existing relationship or starting new ones, to love ourselves first. Important step, our illness doesn't define us!”
- “Don't discount the satisfaction of hugging stuffed animals! I love mine.”
- “ONBottles.com - they promise our ME/LC community a discount… use “water20” for 20% off over $100 purchase.”
- “Love & acceptance for ourselves is so vital, regardless of relationship status.”
- “I think it takes experimenting with different things to figure out what can be satisfying with respect for both of your needs and being intentional about routinely designating time for figuring that out.”
- “Jamison Hill, a severe ME patient who is a writer has a couple good pieces on relationships, especially the first one on this page "Love Means Never Having to Say...Anything" that was in the NYT and his other piece "Life Without Sex" in Men's Journal. https://jamisonwrites.com/articles/”
- "...having extra needs does not make you too difficult, too time consuming, but worthy of compassion and love"--Chanel Miller
- “Vulnerability Over Isolation vlog: https://www.youtube.com/watch?v=WNqswG2Ypes”
- “Therapy really helps! Journaling, gratitude practice also really helped me. Being curious about ourselves & bringing in compassion for yourself helps too.”
- “Found this: https://sexualityanddisability.org/”

- “I share this article when I meet someone new,”: https://www.verywellhealth.com/dating-someone-with-fibromyalgia-or-cfs-4107210”
- “Being creative about physical intimacy can be helpful sometimes. Planning ahead, going slowly, not being committed to a particular "outcome", sleeping afterwards, switching up time of day (night is impossible for me)...all have been helpful. also paying attention to the environment...temperature, low lighting, controlling for distracting noises, making sure I'm as physically comfortable as possible.”
- “You may not have a pet or be able to care for one, but the affection from a cat or dog goes a long way in fulfilling the need for a "hug." There are agencies who make home visits to folks with a trained pet (e.g., a dog that knows not to jump up) and just a short time holding a living, loving being can help fill the need for affection. Virtual hug, in the meantime!”
- “Been using hydrogen water, seems to help my energy levels and sleeping through the night. Able to do some physically heavy, slightly, work and got fatigue but no crash.”
- “In Week 10 of trying this approach”: https://www.healthrising.org/blog/2024/12/24/better-breathing-for-better-health-solve-mes-inspiratory-breathing-study-scores/
- “Someone asked about mental health therapy with an understanding of chronic illness. This is not a personal recommendation, but something that was on my radar: https://www.thechronicillnesstherapist.com/directory”

Resources

- Dating app for people with chronic illness and disabilities: https://info.dateabilityapp.com/
- Living with a Partner Who has ME/CFS and Fibromyalgia, Part 1(BHC): When Your Wife is Ill: https://youtu.be/pvidCgxNw18
- Living with a Partner who has ME/CFS or FM, part 2 (BHC): When Your Husband is ill: https://youtube.com/live/JWCcFCu3ZD8

- Fatigue, Fibromyalgia, ME/CFS and Sexual Health (BHC): https://www.youtube.com/watch?v=E2KJUEhAyHg
- Goode Enough Sex on Good Enough Days: https://www.janesteckbeck.com/events/good-enough-sex-on-good-enough-days

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

- Action for ME (online youth support based in UK)
    - https://www.actionforme.org.uk/18-and-under/support-for-under-18/join-our-young-peoples-community/
- 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/
- Utah COVID-19 Long Haulers
    - https://www.facebook.com/groups/2619858348232191
- 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.