# Support Group Recap: Romantic Relationships and Chronic Illness

*October 8, 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
    - Wednesday, Nov. 13: Legal
    - Wednesday, Dec. 4: Medical
    - Wednesday, Jan. 15: Research
    - Each session will be held at 10 a.m. PT / 11 a.m. MT/12 p.m. CT/1 p.m. ET and last one hour.
    - Registration is available at: https://bit.ly/3Xa4IyW
- 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 and introduced it by explaining that we will discuss the intersection of romantic relationships and chronic illness.

## Discussion Questions

1. What have been some challenges in your love life related to being chronically ill?
2. When it comes to adjusting to your chronic illness, what has helped you in your partnership or marriage?
3. For those who are single, what has dating been like for you with chronic illness?
4. What do you want to know how to face or do in the context of integrating chronic illness into your dating/love life?

5. What do you hope for and/or fear in your love life, in the context of being chronically ill?

**Timothy's shared wisdom:**

- Relationships are the last great frontier. Everyone is trying to figure out their relationships.

- Often, we are trying to ward off rejection in our dating life. I try to encourage people that if someone is going to reject us for our illness then we *want* them to reject us. We don't want them in our life.

- Flexible thinking about what can constitute a date is important. We can loosen our feeling of stuckness by loosening our thinking and approach. Timothy encouraged everyone to practice flexible thinking when dating.

- In any relationship, it is important that for each negative interaction, we have 20 positive interactions to neutralize the negative one.

- Keep in mind that the other person has difficult things to bring into the relationship as well.

- Physical intimacy. Can we be flexible about how we engage in physical intimacy? For example, if we can't engage in physical intimacy, we may be able to talk sexually with our partner.

- When your partner participates in an activity that you can't engage in, be sure to ask them about it when they come back and use the conversation as a way to connect.

- Anger is a secondary emotion that covers a more vulnerable emotion. We can ask ourselves, "If I wasn't angry, what would I have to feel?" Then, we can attend to that underlying emotion.

- Attention is the highest form of love.

- The research on romantic relationships shows that people who get married relatively young have their relationship satisfaction go down when they have children. The relationship satisfaction doesn't go back up until their children leave home.

- We often mislabel empathy as guilt.

- Timothy encouraged everyone to think of the ways we may be underrecognizing and underselling what we bring to a relationship. For example, if you can develop a skill to understand and care about your partner's inner world, history, and daily stress, you can go a long way in connecting with them. It's a rare skill to have a partner or parent who is emotionally attuned, and you can develop that skill for them even from your bed. This can apply to romantic partners and children.

- When we are good lovers, we work to understand the way our partner best feels loved and give that to them.

**Participant comments**

- Participant learned a lot more about herself and grew through the experience of illness. Even though relationships haven't worked out, she has had good experiences. It has reaffirmed to her that it is okay to open up and be vulnerable and let people in.

- Participant had time to date in her 30's after stopping working due to ME/CFS. Met her husband and had a child and is now bedbound. But she doesn't regret marrying and becoming a parent. She wants to be a point of hope for others when there is so little research on pregnancy and ME/CFS. Difficult but worth it.

- Participant has been with his partner for 10 months. They started dating while he was in a crash. They were friends and his partner helped him with doctor appointments and other needs and then it led to dating. It was helpful to be more open-minded about what counts as a date. They would do things like lay down and listen to a podcast when conversation is too difficult. They also do a monthly relationship check-in with this tool: https://www.multiamory.com/radar

- Finding ways to divide the labor even though one partner does most of the physical labor. The lived-experience individual can make phone calls and do research however, the illness makes it difficult to plan for the future in terms of children.

- Sharing BHC resources with their partner has been helpful.

- Intimacy:
    - Everyone's capacity is different, but there might be ways to minimize energy expenditure with props, lying flat, reducing the amount of movement, heart rate monitoring, etc.
    - Props are very helpful. Even just pillows.
    - Participant tries to offer intimacy in the forms that they can such as cuddling, brushing their hair, or making a drink/snack on a hard day. Sex is rare these days but keeping some forms of intimacy flowing helps keep the connection present.
    - Every relationship is different. Participant and romantic partner have done a lot of talking about how frustrated they both are, and it's helped him to know that the participant is also frustrated with his limitations around intimacy. When participant is able, he tries to initiate intimacy, even if it's a 30-second back scratch.

- Participant doesn't disclose in the beginning of possible romantic settings. Rather they disclose about their illness at a 2nd or 3rd meeting when trying to build friendships. Like Timothy indicated, it's better to let people go who aren't going to get it.

- Participant feels a lot of guilt about not being there for her child.

- Participant believes that a lot of time we hurt ourselves by not being able to change our perspective. Her boyfriend noticed they grew much closer than they would have if she had not gotten sick. She agrees there has been deep purpose in this suffering.

- Participant was well in the early stages of her 8-year relationship. Now her partner socializes and travels on his own. She is newly exploring the things she can bring to the relationship even though she is very ill.

- Participant got married while ill with ME/CFS and has been with her husband for 34 years. They adopted twin girls and raised them together. When they dropped their daughters off for college, participant was looking forward to dating her husband again but then got long COVID and became severely ill. She feels like a to-do task on her husband's list.

- Participant stopped dating. She became sick as a young teenager, so it was always hard to tell people about her symptoms and what was wrong with her. Even friends had a hard time understanding. She didn't date much, which is embarrassing for her. She has social anxiety, along with all the other chronic illnesses and got tired of the worrying and the "acting" that she had to do to look fine and normal. Therefore, she decided not to date, and it has been a relief. Being alone is hard at times, but she doesn't want to be a burden to someone. She doesn't see how someone would want to be with her with all the conditions she has now. She worries about her future.

- Participant is going to be courageous and start dating again and try not to undersell herself. She is choosing to believe that there are people out there who can see all that she brings to the relationship and will value her for who she is.

- The dramatic shift of dependency in participant's relationship has been challenging. She wonders how they make space for her partner's emotional and physical needs because he is working a lot more than they had planned and gets less time with their children.

- Participant got sick during adolescence many years ago, so they haven't had experience with dating or romantic relationships before getting sick. While they would like to form a connection with someone, there are so many barriers. They are mostly housebound, and socially feel drained by just occasionally keeping up with family/friends (while also feeling equally grateful for them). They wouldn't know how to start dating.

- When participant became ill, it revealed that she wasn't getting her emotional needs met in her marriage. Her husband is good at emergency situations but not for long-term emotional connection. She learned that it's not a choice, but rather, he doesn't have capacity due to constriction and trauma in childhood. Realizing this helped her to let go of the related anger. Traditional therapy wasn't helpful for her husband or their relationship. They tried a coaching model because it is more about skills. It helped them to understand each other's point of view.

- Participant found that watching TikTok videos with her 17-year-old son enabled them to deeply connect because it started with laughter, and then he would tell her all about his day and what was going on in his life.

- Hearing this session makes me want to not give up on dating.

**Resources related to session**

- Dr. Jordan Rullo
  Fatigue, Fibromyalgia, ME/CFS and Sexual Health (2018)
    - https://youtu.be/E2KJUEhAyHg
- *The Five Love Languages* by Gary Chapman
- Dating apps for individuals with disabilities
    - Dateability
    - Nassrin

- Pregnancy Panel (2011)
    - https://youtu.be/MBk8glip1WU

## 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.