Support Group: Communication in the Context of Being Chronically Ill

July 08, 2025

Announcements

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- Clinical Care Guide
  - https://batemanhornecenter.org/clinical-care-guide/
- Support BHC's One Guide. One Goal $5 Campaign:
  - https://givebutter.com/OneGuide_OneGoal

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

Timothy Weymann, LCSW began the session by explaining how communication bridges the gap of wants and needs as we develop a chronic illness and gain minority status. Quality relationships become paramount requiring healthy communication.

Guiding Questions

1. **What do you notice about your communication with medical providers?**

2. **How has communication changed in your relationships as someone with chronic illness?**

3. **What is it that you wish you would hear from people in your life, related to you being chronically ill?**

4. **What do you find are successful ways to communicate about your illness to anyone?**

Timothy's Shared Wisdom

- Finding providers that have a sense of humility about the work can be important because it makes them better listeners and collaborators.
- It is important for us to manage our emotions within communication to optimize the capacity for the listener to hear us. Occasionally we will deal with other people's personality disfunction.
- It can be helpful to label what we are going through, saying to the provider that you are nervous and thankful to them for listening, so claiming and owning how you are feeling. It also reinforces the relationship and open communication with our provider. It can also be helpful to describe what we are observing from the provider and ask them about it.
- When patients feel frustrated with medical providers, it can help to recognize that providers may also be grappling with their own vulnerability, especially when managing incurable conditions. Just as patients can feel overwhelmed by the chronic nature of their illness, providers may struggle emotionally with their limited ability to offer cures. Depending on their coping skills and personal development, they may respond productively or unproductively. Understanding this dynamic can support better communication. Reinforcing positive provider behaviors such as acknowledging when they listen or try something helpful can ease tension and foster a more collaborative relationship.
- It can sometimes be helpful to keep communicating that some days you will see my illness and some days you won't.
- We should greet ourselves with compassion and gentleness as we start to face and accept our limitations.
- We must practice resilience as we face systemic issues in the healthcare system. For a lot of people, when they face prejudice and discrimination, they become activists. It's hard with what we have going on, but assessing what you can do can be helpful.
- When coping with overwhelming feelings it is important for us to identify that stress occurs when the demands on us exceed our skills and resources to meet those demands. We can allow space for us to be emotional when we first feel overwhelmed and then when that's done, we can move on to problem solving.

- One helpful coping strategy is to externalize the limitations of others by recognizing that when people fail to understand or support us, it's often due to their own poor communication or emotional skills, not our shortcomings or the illness itself. Chronic illness and stress tend to expose existing vulnerabilities in ourselves and others. It's also important to stop trying to convince people who are unwilling to understand. Instead, invest energy in relationships with those who are open and supportive. Support groups like this offer valuable space for connection and validation.
- Hope and connection are essential for coping with chronic illness, even if they come in small forms.

Participant Verbal Comments

- Participant, newly diagnosed with ME/CFS, shared that despite most doctors being unfamiliar with the condition, they were generally sympathetic and open-minded. They were diagnosed by two doctors within two months of getting sick and appreciated that even non-specialists were willing to consider ME/CFS seriously. They noted this might reflect a shift in attitude among some younger physicians and in certain places, showing less hostility toward chronic illness patients. They also felt that presenting their concerns clearly may have helped facilitate more productive conversations.
- Participant shared that they find their appointments go better with providers when they are calm and act as if it is a business meeting. Taking all emotion out of it they have found goes better. They also shared that writing down a list helps them as well. Participant also echoed that they have noticed that younger providers are open to new ideas and approaches. They shared some hardships they have experienced with the UK health system.
- Participant shared that they prepare thoroughly for medical appointments but lose the confidence the minute they step into the exam room even though they trust their current doctor, who has been supportive and caring. However, despite this trust, they still struggle with nervousness and a lack of self-confidence during conversations, especially when discussing more detailed or sensitive issues. They believe this communication block may stem from past negative experiences with other doctors who were dismissive or unreceptive.

- Participant reflected that early on, there was strong interest from their doctors in exploring medications and treatment options. Over time, that interest has faded, and now when they ask about new treatments or adjusting their current regimen, they feel there's little engagement from physicians. Although they've experienced gradual improvement over the past 10 years with some ups and downs, they're still seeking suggestions and feel that continued curiosity and support are lacking.
- Participant shared the unpredictability of their condition, with symptoms fluctuating throughout the day. Frustrated, they've largely given up on doctors and focus instead on maintaining their own health and fitness. They struggle with pacing and find it difficult to communicate their experience both to medical providers and to others in their life who may not understand, especially when they appear outwardly fine.
- Participant shared that it is hard to first accept that they themselves have a problem, and then in turn it is hard to communicate that to others. They also shared they have been trying to dig into the illness more themselves and learn what they can do as opposed to a provider.
- Participant shared that they support using the clinical care guide and recommend selecting snippets that apply to you and bringing them to your doctor to aid communication with them. They shared that they feel fortunate to have a supportive physician and access to resources like the Bateman Horne Center. Despite this, they share the emotional difficulty of accepting and verbalizing the severity of their illness and their depression. Coming from a healthcare background, they still struggle with admitting how sick they are and describing their current isolated life as "house jail". Even with professional support, openly acknowledging their mental and physical health challenges remains a significant hurdle.
- Participant reflected on noticing a decline in their memory, which is difficult to accept given they once had an excellent memory. They haven't shared this openly before and find it hard to admit. They describe how communication has been challenging, especially when surrounded by people who didn't acknowledge their illness, leading to denial and pretending they were more capable than they felt. After living with the condition for 35 years and experiencing worsening symptoms in recent years, they're working toward being

more open, which has been empowering. They emphasize the importance of choosing safe people to share with and suggest that, in medical appointments, it can be helpful to write down or type out questions ahead of time to ease communication, especially when nervousness makes it hard to speak up.

- Participant expressed deep frustration with the current healthcare system, describing it as paralyzing and poorly coordinated. They feel that primary care providers (PCPs) no longer coordinate care effectively or engage with specialist reports, unlike in the past when doctors took a more hands-on, integrative approach. As an older adult with multiple comorbidities, they find it nearly impossible to get clear answers or comprehensive care. They are left managing complex health issues on their own, which is exhausting. While they acknowledge the importance of being polite and strategic in communication, they feel that the quality of care and commitment from doctors has significantly declined compared to 35 years ago when providers referred them to top specialists and actively sought answers. Now, they feel abandoned and are seeking solutions for managing multiple chronic conditions in a fragmented system.
- Participant shared ongoing difficulty with communication, feeling a persistent barrier, especially as conversations often focus solely on their illness. They express frustration with medical appointments, which they tend to avoid due to past experiences of gaslighting and being dismissed, particularly with ME/CFS not being acknowledged. This has made it hard to maintain trust or feel respected by providers. They also reflect on the importance of ongoing internal communication and the emotional toll of constantly advocating for themselves. Despite limited support, they express gratitude for the support group and the few people in their life they can openly communicate with, finding comfort in shared understanding and resilience within the group.
- Participant shared poem they wrote, “I have hope for a moment. I have hope for a day. I hope for tomorrow. I have hope, and I’m free.”

Participant Comments from the Chat

- “I feel like I have nothing to talk about or interesting to discuss outside of my health issues, particularly when people ask me how I am doing. I hate this.”

- "A participant mentioned younger providers understanding better, and I agree. I still am skeptical of older providers who were educated when MECFS was considered by many to be psychological."
- "I have a really difficult time opening up to people because I have been shut down so many times by providers / family members. I don't even talk about my illness around others anymore..."
- "Sad that we can't even trust doctors to actually believe what their patients are saying."
- "I have found some great Myalgic Encephalitis/ME explanations on Pinterest. I shared 2 every day on Facebook for the month of May. I also share other times."
- "Don't be afraid of changing doctors if they don't seem to be interested in your issues."
- "Q 1: I also experienced specialist (7) gaslighting to the point of medical ptsd. What has helped me is realizing my specialists are "practicing" medicine. I give them compassion when they mess up. You know them facing their vulnerabilities. Now I come in confident with discussing the problem. I communicate with a lot of gratitude."
- "A former PCP of mine was not knowledgeable about LC or MECFS, and she just kept telling me, 'I think you're going to get better.' Not helpful at all, and I didn't get better. I found a new primary, who knows a bit more, but more importantly, says she doesn't know."
- "I like the point about providers' vulnerability. I am lucky to have a young PCP with just two other ME/CFS patients and she said how much she appreciates me sharing resources with her so she can learn. Very chill and open."
- "I have a lovely functional doctor who does not know much about ME or long covid. I suspected I had OI and POTS, but a cardiologist dismissed me based on a Holter monitor. Anyway, the functional MD really appreciated the clinical care guide. She was thrilled to have something to help guide her. I pointed to the specific pages, we did a lean test, and it showed OI and POTS. She then used the medicine suggestions!"
- "I have a really difficult time opening up to people because I have been shut down so many times by providers / family members. I don't even talk about my illness around others anymore.."

- "I love the hours w feet on the floor metric. It really demonstrates disability in a quantitative way"
- "Sometimes on my good days I feel guilt instead of joy because people say 'you look fine' and they wonder why I can't show up for other things and days"
- "2) Some people that were close friends, I now have to keep at a safe distance because they are impatient and not understanding of a person with a chronic illness. I've experienced the attitude, 'If you think you can do it, you can do it.' And they imply I am not able to do things because it's my mindset that I don't want to. I share very little with them about my health. And spend very little time with them anymore. 4) If it's someone I've just met, I may share a little information such as, 'I have some health problems,' and then see how they respond. Some want to change the subject. Some ask meaningful questions and we can have a encouraging conversation."
- "I often feel dismissed by others, not my HC professionals, as if they think 'you can do it if you want to.'"
- "House jail is such a great way to describe it!"
- "And I want to do all the things but can't, desire is there but ability to execute is not"
- "I find it helps me when communicating with family and friends is to be non-judgmental with their reactions. It is difficult for people not living with this illness to understand fully what we are feeling and going through. When I am exhausted it is hard to stay grounded."
- "The question about communicating with others is different for everyone. I've been extremely vulnerable online because I feel some can't speak. I want to advocate for our community. What has happened is several friends recognizing they have post viral illnesses, and they have gotten the help they need. Even my family has discovered their medical concerns relate. I've had some friends be my drivers and attend appointments. I've had them talk for me when I couldn't. They got to see what happens with gaslighting and inappropriate things said to complex patients. That was eye-opening to my support team. I think unless a person has this, they cannot fully understand. Being vulnerable with loved ones is hard because they also have grief around the illnesses. I try to be slow with sharing my feelings and give them compassion with their reactions being challenging. They are hurting, too."

- "Sometimes people ask what's wrong with my leg(s) when I use my cane and put my feet up on the cane's folding seat. I'll just say that if my feet aren't up, I tend to get dizzy, and I don't want to fall and crack my skull and ruin everyone's evening."
- "I had dr say after my 3rd appt I don't know what else to tell you/I can't figure it out but I know based on your tests and looking at you I can tell something is wrong. And he referred me out."
- "I usually advocate for myself and request to see the specialist that I need for any illness that the dr can't manage with their own knowledge."
- "I suggest the website Science4me for research info."
- "My Hopkins POTS doc says that everyone with POTS has ME/ CFS. Another Hopkins POTS doc told me that not all POTS/ Dysautonomia patients have ME/ CFS. Go figure."
- "Re complex docs for chronic illnesses and being an older person, find an internist, or if you're lucky, a gerontologist (hard to find)."
- "my strategy is to find doctors who are truly compassionate and don't mind a challenge. its a lot of trial and error to find someone. I started doing consults and asking all questions upfront and laying everything out and then asking how would they approach my care. this way I know within one visit whether this is going to work."
- "My resilience relies a lot on patience."
- "I follow the Open Medicine Foundation and Solve ME on YouTube. They're the ones that are working on all the questions our doctors can't answer. They're flipping heroes, I tell ya!"
- "I would ask the doctor how he or she is doing today. Show care for them as it sets up an empathetic tone"
- "Question 1 communication with providers - as a woman, I've found that with rare exceptions I'm not believed or taken seriously unless my husband is in the room and affirms what I'm saying. Since they kept wanting to blame anxiety, I also now reply that my last 2 psychiatrists said I don't have or meet criteria for generalized anxiety/an anxiety disorder, and that seems to help."
- "I think one of the hardest parts is being misunderstood in our illnesses by others... when we are truly the most reliable narrator of our own story"

- "I try not to take on other people's opinions. I just keep doing me in my experience."
- "I've had long covid for the past 4 years and My parents have tried to blame my symptoms on the most nonsensical things such as eating frozen rice because 'it's poisonous'… it makes it so difficult to communicate with them when they are unwilling to see the truth."
- "I refuse to use my spoons for anything negative. We have so few each day. I'd rather use my energy for things that are important and positive each day"

Tiny Triumphs

- "I had a fantastic first date last night!"
- "I got through a 5-day crash and was able to do some seated gardening which felt so good!"
- "I cooked last night before the food went bad, lol."
- "I allowed myself down time until I started feeling better after a flare."
- "I found the courage to have my brother cremated."
- "I was able to get to my appt by myself, even though it was very hot out."
- "I quit my job so I can focus on my health."
- **"**I took a long weekend solo trip and didn't crash!"
- "I found a way to get my hair washed without it making me crash hard."
- "I started with a new PCP who seems like she's really listening to me and is willing to learn along with me when needed."
- "I received my first pair of prescription grade medical stockings. Day 1 - so far so good"

Resources

- Communicating with your healthcare provider:
  - https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/BHC-HowtoCommunicatewithYourProvider-7.2021.pdf
- Clinical Care Guide:
  - https://bit.ly/4jScKFu
- Take a completed Good Day/Bad Day Questionnaire with you to appointments. It gives the providers an at-a-glance picture of your functionality.

  - https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/Good-Day-Bad-Day-Questionnaire-Fillable-V3-6_6_2022.pdf
- Article shared by a participant great for any relationship, not just a romantic one. https://www.verywellhealth.com/dating-someone-with-fibromyalgia-or-cfs-4107210
- Covid Resources shared by a participant:
  - Beginners guide to Long Covid: https://t.co/1BI5PqSKuH
  - Covid safety handbook:
    - https://linktr.ee/covidbook
    - https://helpforlongcovid.com/treatments
    - What COVID-19 Does to the Body (Eighth Edition, June 2025)
  - RACGP - How COVID-19 leaves its mark on the brain
- BHC 5-min video for lived-experience to share with family and friends:
  - https://youtu.be/gKWk99Fsd_o

Crisis Resources

- Dial 988
  - What Happens When You Call 988? (Article)
- Dial 911
- Crisis Text Line
- Crisis resource page (BHC)

Potential Financial Assistance Resources

- Healthwell Foundation
- Patient Access Network Foundation
- Needy Meds
- My Good Days

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.