

Support Group: Parenting with Chronic Illness-Challenges and Triumphs

October 21, 2025

Announcements

- Sign-up for BHC email to receive the recap:
 - <https://bit.ly/3rnvhjq>
- Clinical Care Guide:
 - <https://batemanhornecenter.org/clinical-care-guide/>
- Support BHC's Mission
 - <https://givebutter.com/BHCSupport>

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 introducing the questions around parenting and how we can continue to be role models even when experiencing complex chronic illness.

Guiding Questions

1. What is the most difficult part for you as a parent with a chronic illness?
2. What would you like to learn how to do better as a parent with a chronic illness?
3. How has chronic illness affected your perceptions of your parenting?
4. What are the benefits you bring your child/children as someone surviving chronic illness?
5. What do you want your children to learn from you as they watch you face chronic disease?

Timothy's Shared Wisdom

- We can preserve a positive self-image amidst our limits by thinking not that we are inadequate but that this situation is not ideal.

- Reflect critically on the “shoulds” that fuel shame and self-judgment. We should question the truth of these beliefs and recognize that self-criticism often acts as a form of “counterfeit control” rather than genuine growth or healing.
- Critically examine negative self-judgments and unrealistic expectations about parenting and life. Look for creative, flexible ways to stay connected and supportive instead of viewing participation in black-and-white terms of being either present or absent.
- Reflect on whether you are in grief or rumination. Grief involves active acceptance and adaptation to loss, while rumination is a repetitive focus on negative events and their consequences, reinforcing helplessness or hopelessness. Acknowledge the reality of losses and challenges but stay mindful of engaging in grief as a process of growth rather than getting stuck in rumination.
- Chronic illness can make someone part of a marginalized group or a “dual minority” if they already belong to another marginalized identity. It’s important to reflect on how much ableism and others’ prejudgments are being internalized and to consciously resist letting those external biases shape one’s self-image.
- Resilience is when people face difficult things and are able to keep moving forward. Resilient people focus on what they can control rather than what they cannot control.
- Avoiding emotional parentification means not using children as emotional confidants about the challenges of illness. This is more important than avoiding engaging them in practical tasks which are common and normal in many cultures. Save emotional processing for supportive adults instead.

Participant Verbal Comments

- Participant shared that they are a parent of two teenagers living with chronic illness and shared that parenting while ill has been challenging but also revealing. Over the past five years, their children have developed deep empathy and compassion from acting as caretakers, becoming more aware of and sensitive to how people with disabilities are treated in public. They also noted how difficult it is for their children to witness others stare or treat them differently when using a wheelchair or neck collar. To model a positive response, they try to demonstrate activism and openness rather than hiding their disability. They

emphasized “holding space” for their children to process their own grief about the situation and approach it together with acceptance and flexibility.

- Participant shared that they are a parent who became ill about five years ago and illness has profoundly changed their family and sense of identity. They lost their career and ability to financially support their children as they always thought they would. They hope to model resilience for their children and show them that happiness and meaning can still be found in life’s small and important moments.
- Participant shared that living with chronic illness while raising three teenagers often brings feelings of inadequacy and exhaustion. They described struggling to keep up with their children’s needs, whether academic, emotional, or behavioral because of limited energy and the inability to be fully present, especially in the evenings when teens tend to open up. Each stage of parenting has brought its own challenges, and this stage feels particularly hard due to fatigue and limited bandwidth. They also shared that using the Visible app has helped their children better understand the invisible nature of their illness. The app allows their kids to check in by asking about their “points” or seeing the data themselves, creating a more compassionate and informed connection within their family.
- Participant shared that they live with their adult child while another is away at college and often struggle with feelings of shame and imposter syndrome related to their illness. They described a recent episode during which their child helped care for them which made them feel guilty and discomfort about the role reversal. At the same time, their children validate their experience, reminding them that the illness is real when self-doubt arises. Despite ongoing tension between gratitude and shame, they are learning to practice radical acceptance, recognizing that their situation simply *is* what it is.
- Participant reflected on both the challenges and unexpected positives of living with chronic illness while parenting. They described the pain of missing important events and being unable to do basic tasks like making dinner, which initially brought feelings of guilt and frustration tied to “shoulds.” Losing their career was also deeply difficult, but it led to rebuilding life with their child as the central focus. Because energy is limited, their child has become their clear priority, and this has strengthened their bond. They also noted a positive shift in their child’s understanding of disability, seeing it simply as part of life rather than something shameful.

- Participant shared an experience of parenting with limited energy, describing how they told their children they could only do one activity together that day. When one child wanted to do both, the younger immediately reminded them that only one was possible and supported that boundary without question. Although it was painful to have to limit such simple moments, the participant felt moved by their child's empathy and respect, recognizing it as a meaningful lesson in honoring boundaries and standing up for those with less capacity or voice.
- Participant shared that they became ill when their children were very young and have mixed feelings of gratitude for the experiences gained during that time, but also regret, wondering if overexertion contributed to their current decline in health. As their children have grown into teenagers, they described a deep sense of compounded grief with sadness of children growing up and the added loss of missed opportunities from years of limited energy. They recognize that despite these missed moments, they were still able to spend meaningful time together and parent well.
- Participant reflected on parenting with chronic illness and finding meaning amid loss. Having been ill for most of their child's life, they described deep sadness over missing simple joys. While it's natural to grieve what's lost, love and presence matter more than physical ability. They emphasized focusing on what the heart can give rather than what the body can't.
- Participant shared how early years of isolation and despair eventually gave way to acceptance, strength, and gratitude. They spoke about raising a son as a single parent, once feeling he was deprived, but now seeing him as a compassionate, successful adult who helps care for his parents. They emphasized that while pain and disappointment are unavoidable, weakness can become a gift that reveals inner strength.
- Participant expressed anger and sadness about their spouse's lack of support and how that dynamic is visible to their children. While their children show empathy and acceptance, the participant feels hurt that their partner does not honor the "for better or for worse" commitment of marriage. They also find comfort in sharing old photos with their now-adult children, reminding them of earlier times when they could do more together.

- Participant shared their story of adapting to illness over the years. Though they are no longer able to join in active outings, they've discovered meaningful ways to stay involved through small, shared activities, like watching fantasy football or anime together. They emphasized the value of adaptability and finding joy in small, everyday moments of connection.

Participant Comments from the Chat

- "Not being able to provide for and participate in the experiences that I had always envisioned."
- "Never give up hope life can change at any moment miracles happen and blessings can be found even here in the valley."
- "I think men (and especially dads) with chronic illnesses have an extra layer of psychological burden that most women don't. I empathize with what you're going through."
- "You will always be their father and hopefully they will recognize your love for them."
- "I feel the pressure of not being able to rise as much as I would like."
- "I am a parent of adult children, but I am a grandmother to a very busy 3-year-old. I always thought I would be able to be present in my grandson's life, but I find I am hardly able to see him let alone play with him. My kids grew up with my illness, and they are used to it, but I am afraid he will not understand why I can't do more. My hope is he will learn more empathy and understanding for people with different needs because his grandmother is someone who does."
- "Letting my teenager's slide. I've even been told by their father that I need to get after them for them to be held accountable. My kids have held years of anger at me. It's been so hard as a parent."
- "Yes, can relate to teenagers up late talking and I'm sleeping so miss the talk time. Now they are away at university, so I schedule Weekend afternoon talk time."
- "I can't figure out how to raise my hand on the web browser version, but my young son (age 6) has learned boundaries well. His older brother wanted to do 2 things after I said I could only do one. Littlest son backed me up and said 'no! Mommy said she can only do one. We have to pick.' He has learned respect for

women and boundaries through this. Broke my heart that I could not do two things, but made me feel good my little child 'got it'".

- "I also have teenagers and I constantly remind myself that in the 80s (when I was raised) my parents didn't even know where I was most of the time. I turned out really pretty well -regardless. This (often) helps me get through the day."
- "The teenage years are tough with the energy challenges. My kids are young adults now. They turned out well despite my limitations. And we are close, and they are now my friends and such a strong support. Hang in there, what you're doing is enough."
- "I was with women talking about our greatest challenge. Mine was that I don't enjoy being a parent of teenagers. I feel shame about that. It's been one fire putting out after another. With the illness and parenting, my spouse and I feel overwhelmed. We know a third of their childhood has been with a severely sick mother. It's been so tough."
- "Concentrate on what you can do and not what you can't do. Focusing on the negative or things you can't control is a waste of precious energy. Miss a birthday, have it on another day, etc..."
- "I think the most difficult part as a parent with a chronic illness, is also trying to continue to take care of my now adult child with a chronic illness, especially on really bad days. The upside is that she gets it and understands, since it's the same illness. Does anyone else have this situation?"
- "I love that for her! (I'm autistic and got diagnosed age 28. I wish I would've had the awareness, support and normalization at a young age; my parents are probably chronically ill and neurodivergent themselves, but they didn't have the awareness, and didn't develop skills to communicate openly and healthily with each other or me)."
- "Jessica Kellgren-Fozard on YouTube is terrific about parenting. She has multiple invisible illnesses and she and her wife just had twins!"
- "I can relate to this, Lisa. My now 18-year-old daughter (who still lives with me) also has a chronic illness, and it becomes extremely challenging to help her on days when we are both in flares. I start to feel like a "failure" as a parent, especially since I am a single mom."

- “Thanks for sharing... I miss my career so much, but what you said resonated, I was always pulled in so many different directions when I was working, and this illness has simplified my life. What energy I have goes toward my son.”
- “There are major losses here. I hate missing things too - saying later until it is deferred too far. It is so hard.”
- “I too pushed too hard and too long and now a not in a good place. Today I have a new list of things that we can do together. I have had to change my mindset as my grieving was causing me more fatigue.”
- “‘Adjustments’ (like reasonable adjustments) are something these communities can help us come up with to help stay engaged while reducing expenditure of energy. E.g., can't join day out or holiday - but can call, or write a letter in advance, or video chat and ask them to do an activity like find 5 pink things to tell me about, which means you're 'there' and involved even when you can't be directly.”
- “I'm working a lot on accepting my disability-related needs and limitations and having boundaries around that, but that has definitely led to grieving of losing out on quality time with loved ones (including friends) when it turns out they're not willing to make an adjustment so that I can be included (this has included things around COVID precautions/risk and also not being able to do anything beyond a flat hike, and also not socializing in sensorily overstimulating environments, since I also have sound sensitivities.”
- “A friendly challenge: Do you only remember the big special occasions from your childhood? Or is it memories of novelty or a cuddle or a kind word?”
- “I just had a birthday and was unable to do anything but lie on the couch. I'm so sorry you will miss out on your festivities. We did a family movie night in place of going out and it wasn't perfect, but it was okay. Wishing you the happiest birthday possible.”
- “My therapist gave me some insight this year. She has many clients who had parents with disabilities or were very ill - and she said not one of those people was bitter or resentful about it and thought of their parents lovingly. There is a true presence and quality of interaction that comes with being profoundly ill and truly valuing time together when it's possible.”
- “My therapist helped me to reframe how I think of how I can contribute in my grandson's life. So, if I can't go trick-or-treating with him, for example, I can

participate in ways that I can. I can bake cookies or Facetime with him after he comes back and talk about what he did during his outing. Even though I can't be there, I can be there the best I can."

- "I have found sharing their pictures for the week is a great past time. We screen share them on the tv and they love talking about themselves and their friends and all the things they have been doing. It's a great way to get to share their activities and interactions, relationships and have some input and share advice etc. Their pictures are all so different and such a reflection of their personalities and they love sharing and talking about themselves. It's a great way to stay involved without exertion."

Tiny Triumphs

- "I didn't catch a cold my family had the last week! BAM! ✨"
- "Been able to help my son with his homework the past couple days!"
- "I was able to make a wonderful orange almond cake with my child for their 13th birthday on October 14th! And a friend of ours and my child paddled me around on the local marsh in a canoe."
- "Slept in."
- "I finally got some therapy for my ailing hand."
- "I'm upright and working from home today."
- "I Showered."
- "Played with dogs."

Resources

- ME/CFS Parents UK
<https://www.facebook.com/groups/mecfsparents/?ref=share>
- Pregnancy and Parenting with ME (international group)
<https://www.facebook.com/groups/1502176813410132>

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/invisiblyouthgroup>
- 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 Parents UK
 - <https://www.facebook.com/groups/mecfsparents/?ref=share>
- 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.
- Pregnancy and Parenting with ME (international group)
 - <https://www.facebook.com/groups/1502176813410132>
- 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 10:30 p.m. PT / 1:30 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](#).