

Support Group Recap: Improving the Holidays when Chronically Ill

12/12/23

Recap

Announcements:

- Meredith is in a crash but recovering and doing better with time. Her family got a new dog, which is providing a lot of joy. She is wishing you all happy holidays and looking forward to rejoining us in the new year.
- Sign up for e-news: <https://batemanhornecenter.org/outreach/newsletter/>
- Donate to support BHC: <https://batemanhornecenter.org/donate/pay-form/>

Today, we are sharing strategies for keeping the holidays fulfilling.

Common Things That Can Make the Holidays Psychologically Difficult

1. Stress of doing too much or wanting to do things "perfectly".
2. Expectations not meeting reality. Idealism and pressure crashing against the moment's reality.
3. Grief and loss - lost loved ones, abilities; capacity to celebrate holidays like one did in the past; pain of discrepancy between now and then (nostalgia of "better" holidays).

Group Discussion:

- It can be hard to open Christmas cards from family & friends. It's overwhelming, considering the state I'm in. In the past I haven't sent out greeting cards, but this year I did, and that's something to celebrate.
 - Sometimes the holidays are a stark reminder of how our life is different from a lot of other people's lives and from our former selves. If grief comes up, honor it – express it (cry, share, try not to ruminate). You can even send a mass email or text message. Ask people to reach out to you, if you'd like.
- This is my first Christmas not doing well and not able to do much of anything. Getting cards from friends out of state has given me the opportunity to reach out, thank them for the card, and reconnect. It's nice because I don't have to initiate the effort. My fiancé has been supportive, and he helps to facilitate connection.
 - We tend to compare ourselves to one snapshot – one photograph on a Christmas card. We don't see the behind the scenes. They are putting their best foot forward. We know everyone else is having issues too. We need to ground ourselves in reality. Mental health is a commitment to reality at all costs. Reframe when we need to. Utilize boundaries when we need to.
- People don't believe me, even my own brother and sister. It's tough because people see me when I'm at my best. I started a YouTube channel, and it's so great to have so much connection.
 - It's great that you are not letting your condition define you. You are figuring out what works for you.
- I would like to be invited to more things, but people know I don't have a lot of stamina, and therefore I'm not invited. I feel left out and even more isolated. I would like the opportunity to be invited and be able to respond with a yes or no.
 - It's important to directly communicate. Share with your family that you want to be included and that your feelings were hurt. It can be hard,

because it requires us to be vulnerable. We can utilize the counteroffer....”I can’t come this time, but I’m available to chat with you on the phone this Friday afternoon at 2pm.”

- I typically spend the holidays alone. I wasn’t able to go south due to a water leak in my rig. I’ll be stuck in the house, instead of being nomadic in my RV. My mother was thrilled, because she will get to spend the holidays with me. Everything happens for a reason – I have an additional challenge with a torn calf muscle. Now I have help, and I’m not down south and alone.
 - It’s great to be flexible and adapt. It’s great to make the best out of whatever is happening at the moment.
- It hurts my feelings that I’m the last thought when being invited by my sister. I’m chemically sensitive, and she painted her home days before, and I couldn’t go. It’s a complicated relationship.
 - It’s hard when we need people in a certain way, and they do not have the capacity or desire (or both). Sometimes we need to accept that people are non-compliant and redirect our boundaries and expectations. It’s okay to reiterate our limit. & remember that some people don’t want to understand. Self validate. Give yourself grace and compassion. Redirect your efforts elsewhere. “Don’t seek water from dry wells.” Reinvest your energy where there is water.

Tips from the Chat

- I wanted to let people know about a new resource from #MEActionNC - Help ME Bingo. It is a game designed to help a family to learn a bit about what it takes to deal with this illness or to help people w/ME to remind themselves of the coping strategies that can help to reduce crashes after holiday events. You can find it at the @MEActionNC Facebook page or at:
https://docs.google.com/document/u/1/d/1Abo0evmSR8U5t6uuuYrrm5UL9_Piz_G2d4JbzsGBgYU/edit?usp=sharing&fbclid=IwAR2XbEtR3a-2iXWiklbXsRIFonzl-Q-s9MoMOjCDDqASr0EjMevLSZHaGVk

- <https://www.meaction.net/2022/12/08/facetsofme-centering-me-during-the-holidays/>
- Couple books on communication that I've found super helpful! "Crucial Conversations" "Difficult Conversations," "Non-Violent Communication" 😊
- On YouTube there are great videos by Marshall Rosenberg speaking about Non-Violent Communication if that's more accessible ❤️
- A neighbor wrote one lovely card and posted it in the common area for the entire building to enjoy.
- NIH ME/CFS Scientific Conference
- <https://web.cvent.com/event/efc45a4d-bcc1-4832-b537-8905ae828077/websitePage:fa2d773d-e952-4e10-8ccf-f70dd0296da5>

Tiny Triumphs

- I went to doc this morning for another reason, and found the CNA "got it"
- I made it downstairs to the kitchen & living room after being 100% bedbound for 1.5 years 😊
- I went out to Chuck-a-Rama for lunch on Sunday.
- We bought a dog so all my energy goes there currently, but I needed a couch buddy and it has changed my life for the better.
- My dog Charlie is my little couch buddy :) it's nice company having a pup around
- I honored how terrible I physically felt yesterday and canceled a holiday outing with a friend that I had set up months ago. Tried not to get mentally discouraged and forced myself to try and rest.
- I walked 14 minutes. Of course, I went to bed after but it still felt great because it was beautiful to be outdoors.
- I got out of the parked car to go to a store to buy something and got back in. It all went well 😊

- I'm still here for the holidays!
- I took a shower today 😊
- To not be fast paced and just be. Be in the moment with my family around the Christmas tree.
- It's amazing to hear the hope from the NIH ME/CFS Conference. We are moving forward, and it's really encouraging.
- Thank you for sharing the hope. There's a difference between healing and caring.
- I made the family recipe Christmas cookies today. My annual bake.