Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION

Thank you for joining the 1/9/2024 Support Group where we discussed "Hopelessness and Suicidality."

Please note: *If* you are in a place of crisis and considering taking your life, **we need you to call 911, 988, or go to the nearest psychiatric crisis center or emergency department in your area. Your life matters, and it matters to us.**

The following resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance nor endorsement.

Subscribe to receive monthly emails with the support group and L&L recaps.

Resources:

- **Crisis Resources**
  - **Dial 988**
    - What Happens When You Call 988? (Article)
  - **Dial 911**
  - **Crisis Text Line**
  - **Crisis resource page** (BHC)
- CDC Resources
- Suicide & Chronic Illness
- Identifying and managing suicidality in ME/CFS (publication)
- Administration for Community Living (Resources)
- When a Diagnosis Requires a Long Term Money Strategy (Article)
- Multiple Chronic Conditions Resource Portal (website/resources)
- Utah Intermountain Health Access Center (website)
- AMMES Financial Crisis Support
- AMMES Helpful Links (many different resources)
- How to be Poor in America (website/resources)
- United Way (dial 211 or visit website for local resources)
- Caring Bridge (website/resources)
- #MEAction Resources/Support
- Coming soon: MEAction's Canary Corps program to help people with ME, LC, and other infection-associated chronic illnesses find and access local services and support for people with disabilities. https://www.meaction.net/canary-corps/

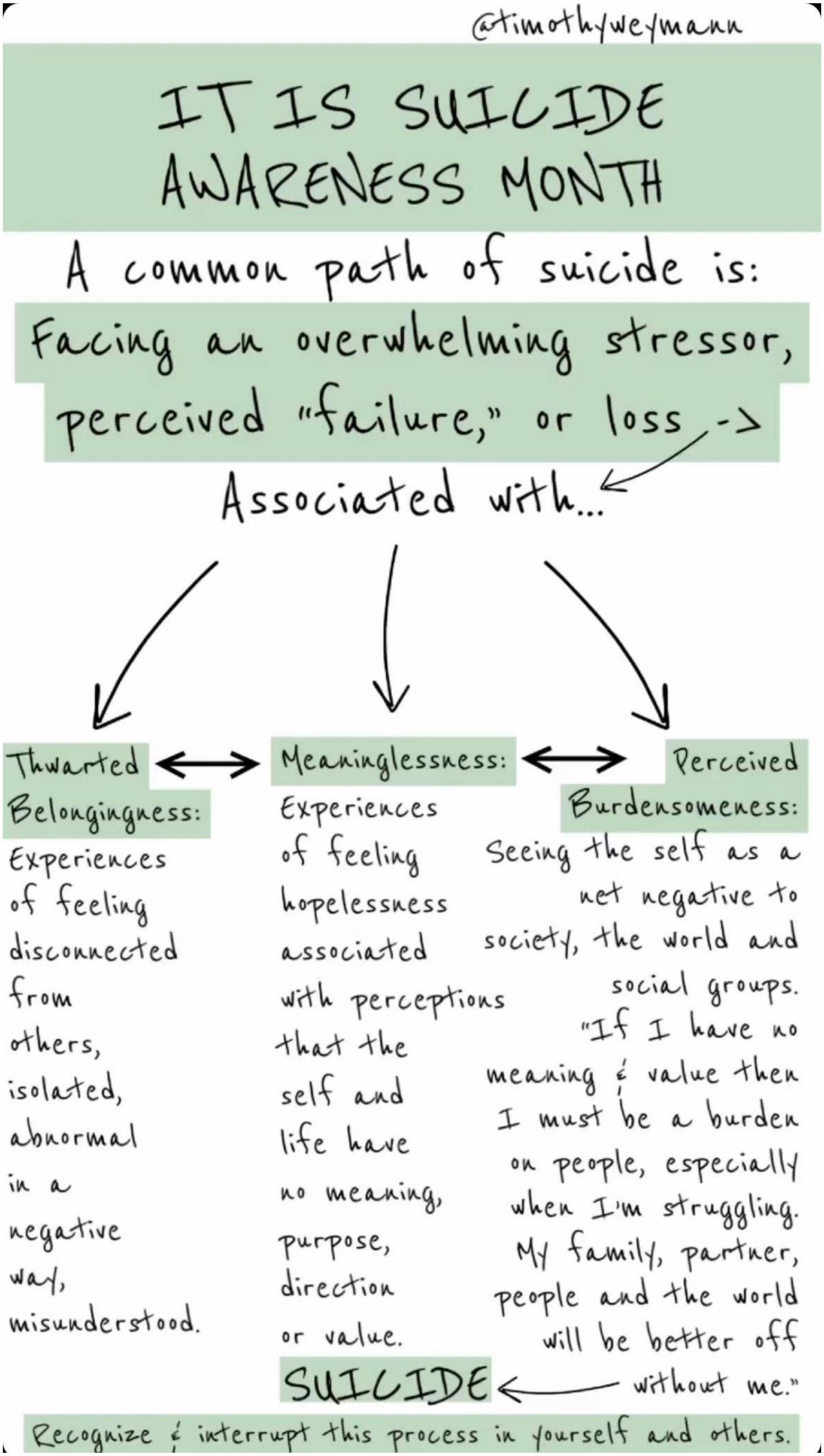
Additional resources shared by participants

- **Facebook Groups**
  - **Surviving with ME**
    - https://www.facebook.com/groups/695317212152964
  - **ME/CFS Social Group**
    - https://www.facebook.com/groups/1202428297198122
  - **CFS/ME Friends**
    - https://www.facebook.com/groups/CFSMEFRIENDS
  - **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
  - **ME/CFS phone support group**
    - Occurs on Saturday nights at 8pm, EST.
    - Call: 609-746-1155. Punch in: 915110#. Group is open to all.
  - **#MEAction Living w/ME Support Group**
    - https://www.facebook.com/groups/211058135999671
- Tara Brach's work
  - RAIN: recognize, allow, investigate, nurture
- Cards
  - The Rest Deck (deck of cards)
  - E-cards
- App
  - "I Am"
- Book
  - How to Live This Year as if it Were Your Last (Stephen Levine)
  - Ambiguous Loss (Pauline Boss)
- Finding a therapist
  - Psychology Today (search by area of expertise, location, insurance, etc.)
- Chronic Market (products made/sold by individuals with ME/CFS)

__See list below for additional resources shared during past support group sessions__

Timothy introduced a framework for understanding hopelessness and suicide.

- The framework outlined a common path to suicide, beginning with overwhelming stress and/or perceived failure, and explored three interacting processes: thwarted belonging, meaninglessness, and perceived burdensomeness.
- These processes were discussed in the context of the challenges faced by chronically ill individuals, highlighting feelings of disconnection, isolation, and the struggle to find meaning.



@timothyweymann

IT IS SUICIDE AWARENESS MONTH

A common path of suicide is:

Facing an overwhelming stressor, perceived "failure," or loss ->

Associated with...

Thwarted Belongingness: Experiences of feeling disconnected from others, isolated, abnormal in a negative way, misunderstood.

Meaninglessness: Experiences of feeling hopelessness associated with perceptions that the self and life have no meaning, purpose, direction or value.

Perceived Burdensomeness: Seeing the self as a net negative to society, the world and social groups. "If I have no meaning & value then I must be a burden on people, especially when I'm struggling. My family, partner, people and the world will be better off without me."

SUICIDE

Recognize & interrupt this process in yourself and others.

- Participants discussed how feelings of isolation and disconnection often stem from societal and healthcare dismissal and disbelief; making it a challenge to be vulnerable and honest about the reality of the disease/illness and the mental/emotional toll it takes.
    - Ableism and toxic positivity were two themes that arose during the discussion, supporting the notion that this is not helpful nor productive nor realistic thinking and further leads to feelings of isolation, shame, and burdensomeness.
        - Participant feedback
            - I've been helped a lot by learning about ableism and internalized ableism. Reorienting my thinking helps release a lot of negative self-judgments and assumptions about what it is to be "valuable".
            - Anyone have tips on how to respond in the moment to someone who says "just be positive" when you are trying to share these feelings (say with family)?
                - When someone tries to promote that kind of insensitive positivity to me I tell them straight up that that is not helpful, what I need is ____. (Someone to just listen to me vent, someone to just check in once in a while to say hey so I don't feel forgotten, etc.). Or sometimes I flip it into a situation where people may understand it (is this what you would want to hear from someone if this was happening to you?) most of the time people just go quiet. One person continued to be a jerk so I hung up on them 🤷‍♀️ don't have energy to explain to people that don't want to understand.

- Participants encouraged finding a supportive and understanding therapist, counsellor, or coach who has experience with chronic illness and ambiguous loss.
    - It is also important that when you do find a compassionate professional, that they know about your disease.
    - Direct participant feedback:
        - My mental healthcare team has been proactive about learning about ME/CFS to integrate that knowledge into the support they provide… that should be the professional standard, period. Ask for it expect it, call it out when you do not receive it or see others experiencing poor support.
        - I heard about Internal Family Systems therapy through 12 step recovery, and finally found a therapist (in my rural area), who is new and also pretty good.
        - I have a somatic therapist that I meet with online once a week. Though she doesn't have a background in ME she is present in the moment and tuned into the experiences of the body in a way that feels connecting.
        - I found a counselor who works with hospice patients, and she has a great understanding of chronic illness, although the 2 are quite different.
        - It is SO helpful to have support from a professional who understands the issues we deal with living so I'll all the time. Suggestion: contact a local hospice organization to see if they can provide you with a list of counselors.

The conversation also touched upon the broader societal issues influencing mental health, including economic and healthcare system challenges.

- Participants expressed frustration with the lack of understanding from healthcare providers and advocate for a professional standard that includes a comprehensive understanding of specific conditions, such as ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), Long COVID, fibromyalgia, dysautonomia, etc.
    - Direct participant feedback: We may not feel a burden initially, but ongoing lack of support (or even acknowledging that we are ill) from healthcare providers, government/welfare/social etc. can erode our sense of self, dignity & worth.

- Another core issue is the lack of resources and support in accessing resources to help with everyday living.
    - Discussion arose around what resources are available state-to-state and federally.
        - *Please see the above list for more detail.
    - Participants also discussed frustration when reaching out to crisis hotlines and healthcare professionals and being met with dismissal, disbelief, and/or general lack of guidance.

Participants shared insights into how reorienting one's thinking and focusing on the external situation rather than internalizing can be empowering and freeing.

- Internal dialogue: Do I not want to be here anymore vs. do I want relief and peace and rest?
    - Direct participant feedback:
        - I find hope in the fluctuating nature of the illness. Yes, I have bad and hopeless days, but I know they always pass. I know the good patch will come again and that helps me get through the bad patches. I also remember that depression happens when I am in a crash and stops when I am out of the crash. I try to think of it as one more symptom that will pass with rest.
        - When it’s bad emotionally, I tell myself “Just hold on. This will pass. It will get better.”
        - Reasons for living
        - Please do not deny the world the benefit that you bring to this world.
        - Taking as a day by day moment
        - I found that creating a support group and sharing lived experiences to raise awareness helped me find new meaning and purpose in life
        - I went to a once a week group on something not related to illness and it really helped to ‘be with’ other people. It gave me another window besides what my mattress had to say. It did cost spoons but gave me a real lift as I felt part of the world out there.
        - If I see my identity as small, then my life becomes small.
        - Power of fears and feelings – when in this place you are so hyper focused that you forget any positive input

- When I first started my daily gratitude practice, it felt fake. But I kept it up and 10 years later it's made a huge and beautiful impact. I'm so glad I stuck with it.
- Action and adaption
    - Taking action to understand what's happening and adapting to work with your illness.

How can we support friends who are struggling?

- Direct participant feedback:

Just listen without shutting down the conversation or trying to convince them otherwise, their feelings are their own, let us be heard, that's usually half the reason people feel alone enough to consider suicide, or it was for me.

Resources shared in previous support groups

What resources and services have you found helpful in managing daily life/tasks?

- Home delivery services
    a. Food delivery (pre-made or easy to cook)
    b. Amazon Prime
    c. Walmart online grocery
    d. Keep the reorder option to lessen the cognitive demand
    e. Fresh Bakery
- Living and home supports/services
    a. Concierge Home Health Service
    b. Community Caregivers: match volunteers with those in need of assistance.
    c. NextDoor.com
    d. State waivered services
    e. Medical equipment
    f. Synergy Home Care (locations throughout the U.S.)
    g. Occupational therapy
    h. United Way
        i. 211unitedway.org
        ii. Call 211 and enter your zip code
        iii. Unitedway.org (world-wide)
    i. Look into local senior centers for resources.
    j. Housing
    k. Guide to getting mobility & medical equipment
    l. The Child Life Department in each state can help with developmental, educational, social and emotional support of children of all ages.
- Cleaning
    a. Ask for cleaning supports/services through local town's Facebook page.
    b. Angi's List
    c. Buy a robo vac
    d. House Cleaners Utah (may have for other states)
    e. Home Instead

    f. Right At Home
    g. How to Apply for a Disability Home Aid
- Food/Cooking
    a. Pre-made food (salads, meals, etc.)
    b. Chef for Seniors
    c. Hungry Root
    d. Home food delivery via territoryfoods.com
    e. ImperfectFoods.com (nationwide)
    f. 4PFoods.com (Washington DC, Virginia, Maryland, Eastern Seaboard, and MidAtlantic)
- Medical support
    a. CallOnDoc.com **(*Use caution as these providers do not know about your illnesses and the credentialing process is not well known*)**
    b. UCHealth has a program called Enhance Wellness.
    c. Medicare: https://www.ssa.gov/medicare/sign-up
    d. Consider reaching out to medical students who need hours and have them help you with your paperwork, learning about comorbidities, understanding medications, etc. Great, untapped resource.
- Transportation
    a. In Utah's Salt Lake Valley: The Utah Transit Authority has an A.D.A. Paratransit support system where they will transport you where you need to go, for free. 801-287-2263
    b. Mobilizing: using motorized carts in the stores or getting a powered wheelchair; scooters, etc.
    c. Easter Seals
    d. National Aging & Disability Transportation Center
- Communicating illness
    a. Cards: https://stickmancommunications.co.uk/products/
    b. Crash Survival Guidebook Communication Cards (BHC)
    c. Chronic Illness: What I Want You to Know (BHC)
    d. Insights into My Chronic Illness (BHC)
- Pacing resources
    a. Tachymon
    b. Heart rate monitors
        i. **Heart rate handouts**
            1. Heart Rate Variability (BHC)
            2. Heart Rate Monitoring (Workwell)
        ii. Stat-health.com
            1. An ear wearable that is being developed to track blood flow.
            2. HealthRising has a blog on this
        iii. Elite Heart Rate Variability
        iv. +HeartMath
        v. Apollo wearable
        vi. Smart watch – tracking heart rate and sleep quality
        vii. Garmin Watch – tracking heart rate
        viii. Visible or Visible Plus is a good app for tracking heart rate and HRV and gives you a score.
    c. MEAction Pacing Guide
    d. Crash Survival Guidebook
    e. Set activity alarms

    f. Using mobility aids
        i. Scooters
        ii. Wheelchair (power)
        iii. Cane
        iv. Cane with seat
- Apps for tracking symptoms
    a. mySymptoms
    b. You + ME

- Disability Discussion:
    - Social Security's Policy on Evaluating ME / CFS - Policy 14-1P Social Security SSA
    - Getting Disability by Arguing You Can't Even Do Sedentary Work Nolo
    - Navigating Disability - SolveME (video) or PPT materials For Employer disability plans – SolveME
    - Long COVID & Fatiguing Illness Recovery Program's ECHO gave an excellent lecture on disability