

**Coping with Chronic Illness
Facilitator Guide**
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Before the group begins:

- Read through the entire facilitator manual to familiarize yourself with the topics and themes.
- Send patients the pre-group message, which includes details and pre-group outcome measures. Use smart phrase “.CWIMHCMESSAGEPREGROUP”
- Make sure the group is scheduled correctly on the Epic clinic schedule
- Discuss with your co-facilitator how you want to run the sessions
- Familiarize yourself with the group note template “.COPINGGROUP”

Other group considerations:

- You will likely want to share your screen at times, be prepared to do so, but also stop screen share to promote discussion
- The priority for this group is for participants to connect with one another – allow them to talk, leave silence and space for them to discuss amongst themselves
- You may have to remind the group that what they’re saying is important, but because there is content to get through, we will be interrupting them at times
- Directly request/invite participants to talk if they tend to be quieter; try to promote each person sharing as equally as possible

Session 1

Set up

- Help people connect via zoom; make phone calls as necessary to help them get connected to group – this will usually take up to 15 minutes on this first session
- Tell people to use the “gallery view” option so they can see each other; review mic and camera buttons.
- Once everybody is in attendance, ask if they have completed the questionnaire in their MHC message. If not, request that they do so after this first session

Introductions

- Introduce facilitators (name, pronouns, role) – will do group intros later
- Review the group rules and expectations (page 5)
 - Take turns reading between facilitators and/or ask participants to read as well
 - Ask the group if they’d like to come up with any other rules.
 - Structure of group
- Ask people to raise their hands if they’ve experienced issues with the following:
 - Pain, fatigue, sleep, leaving the house, working, the healthcare system, socialization, low self-esteem.
 - I usually don’t ask people to share at this point. After going through each category, I point out how many people in the group share similar difficulties despite very different diagnoses.
- Discuss how past group participants have found it helpful to meet others with this shared experience of chronic medical illness given how isolating it can feel. I talk a bit about how the first couple of sessions we talk about how the illnesses have affected their lives, which can be a bit sad, but the last few sessions address what we can DO about that.
- Go around and have people introduce themselves. Give them the option of sharing a little about their medical illness and how that’s affected them, but let them know they only need to share as much as they feel comfortable with (especially regarding diagnosis).

Break (3:50)

Topic 1: Discuss Issues Related to Having a Chronic Medical Illness (page 7)

- Ask participants ways that their medical illnesses affect them or interfere with their lives
- Discuss as the topics arise
- Emphasize topics from page 7 that don’t come up naturally; share screen and review page 7 with them to cover all of the topics

Topic 2: Discuss Grief (page 8)

- People with chronic medical illnesses might grieve the life they imagined they would have, the body they thought they’d have, the activities they thought they’d get to do more easily.
- Share screen and review page 8 – ask participants to take turns reading and discuss each topic

Topic 3: Introduce concepts of Acceptance and Mindfulness

- Review acceptance page 9 in session if time allows
- Introduce concept of mindfulness page 10. Let participants know we’ll be doing a new mindfulness exercise each week.
- Lead the mindful breathing exercise.

Practice

- Encourage participants to read the Acceptance sheet on page 9 if you didn't get to in session
- Review Practice assignment (page 11)
- Answer any questions

Wrap up

- Answer any questions
- Remind them to complete the questionnaires if they haven't
- Remind them to connect to group the same way we did today – with this zoom link
- Let participants know they'll have time to check-in with one another in a breakout room before we begin the structured part of session and that we'll check in about their experiences with practice assignments.

Session 2

Check-In (allow up to 30 minutes)

- Briefly say hello to participants and then put them into a breakout room (or rooms depending on group size) to check in with each other
- Bring participants back to the large group room, ask them how they're doing this week, to share about their Practice, and anything else that came up during the breakout room check in
 - Reflections from last week/practice + what they hope to get out of group
- Allow each participant to share
- Check in about pre-group survey
- Review page 12/introduce the session topic

Activity

- Review page 12-13 – values clarification
- Allow participants some time to review the list of values on page 14
- Discuss page 16 activity – tell participants that in their small groups, you would like them to discuss answers to one or two questions on page 9 for about 15 min and then we will discuss with the larger group
 - Break people into 3-4 person small groups
- BREAK
- Discuss their responses to the questions in the larger group – allow them time to connect with each other
- Review page 17 (mindfulness in daily activities)

Practice (page 18)

- Discuss living with a chronic illness as only having a certain amount of energy and time to put toward activities. Because of that, they have to decide what is most important, or valuable. For this activity, you only have \$95 – within that budget, select which values are most important to you.
- Let participants know that they may write in their own value in the blank spaces if they don't see what they need listed.
 - We will discuss this at the beginning of next week

Session 3

Check-In (leave up to 30 minutes)

- Briefly say hello to participants and then put them into a breakout room (or multiple rooms depending on group size) to check in with each other
- Bring participants back to the large group room
 - How is everyone today? Any reflections on last week's session?
 - Review Practice (values mall)

Topic 1: Emotions

- What are emotions – can anyone define what an emotion is or provide an example?
 - There is no single agreed upon definition, but one example is: “Emotions are reactions that are experienced in response to events or situations”
 - The type of emotions we experience depends on circumstances (e.g., joy or relief at good news, fear or sadness in response to bad news).
- Emotions have a strong influence on our daily lives and the decisions we make
 - Can anyone provide an example of when an emotion influenced your behavior?
 - Has anyone ever had a difficult time managing emotions when under stress?
- Why do we have emotions?
 - Emotions let us know what is important in life and when a problem exists.
 - Briefly review fight-flight-freeze mind body connection
- Foster discussion regarding unique triggers for strong emotions

Break

Topic 2: Stop and Slow Down

- Discuss cues to notice emotions
- *Notice how physical sensations of emotions can mimic or exacerbate symptoms of illness*
- Review the slow down strategies and elicit additional ideas from group
- Note different strategies can be used in different situations

Topic 3: Supplemental problem solving sheet

- Briefly orient participants to the supplemental problem sheets in accordance with session time.

Activity: Meditation (page 32)

- Facilitate Body Scan Meditation and briefly discuss

Practice (page 33)

- Use the stop and slow down techniques – makes some notes about the emotions you noticed and the strategies you tried.

Wrap up

Answer any questions ; Remind them to connect to group the same way we did today – with this zoom link.

Session 4

Check-In (allow up to 30 minutes)

- Briefly say hello to participants and then put them into a breakout room (or multiple rooms depending on group size) to check in with each other
- Bring participants back to the large group room, ask them how they're doing this week, to share about their Practice (i.e., values mall, mindfulness in daily activities), and anything else that came up during the breakout room check in.
 - Reflection from past session

Topic 1: Leaves on a Stream

- Guide participants in the leaves on stream exercise page 29 to for experiential introduction to noticing thoughts
- Discuss as a group – how many thoughts did you have? How many times did your mind pull you away from the exercise? Was it hard to get unhooked from a thought?

Break

Topic 2: Introduce unhelpful thoughts

- Discuss the nature of thinking and that our minds are always busy trying to solve problems and ward off danger, this is in part how humans have been a successful species.
- As human beings, we all automatically respond to situations with potentially unhelpful thoughts. Sometime we take cognitive shortcuts that are inaccurate.
- Review Cognitive Distortions
 - Have participants discuss which of these thought traps they notice themselves using
- Review step to reframing thoughts; discuss benefits of practicing this (e.g., get in the way of living values and solving problems, perpetuating negative emotions and physical tension).

Topic 3:

- Introduce Cognitive de-fusion as another tool to cope with unhelpful thoughts
- Review different strategies to de-fuse from unhelpful thoughts
- Elicit feedback from participants. Which ones will they try?

Practice (page 34)

- Practice the Leaves on the Stream Meditation (recording provided) or the other mindfulness activities we have reviewed.
- Practice noticing your thinking traps and using some of the cognitive skills
- Make some notes about your experience to share next week

Wrap up

- Answer any questions
- Remind them to connect to group the same way we did today – with this zoom link

Session 5

Check-In (allow up to 30 minutes)

- Briefly say hello to participants and then put them into a breakout room (or multiple rooms depending on group size) to check in with each other
- Bring participants back to the large group room
 - Half-way check-in – are you getting what you want out of group?
- How are you all today? What are your thoughts about last week's session?
- Review Practice: Body scan meditation, stop and slow down for emotions

Topic 1: Why is communication important (3:30 – 3:45)

- Introduce and normalize that chronic illness can impact our relationships
 - Managing symptoms (e.g., getting needed rest, attending appointments) can reduce our time, energy, and desire to interact with others
 - People in our lives will respond to illness in different ways
 - When others don't understand our experience, we may lash out or withdraw.
 - It can become difficult to balance our need to have healthy relationships and healthy boundaries - verbal and non-verbal communication is an important ingredient for both
- Foster discussion regarding how others may respond to illness
- Review strategies to improve communication

Break (3:45 – 3:50)

Topic 2: Assertive Communication

- Introduce assertiveness in context of chronic illness
- Psycho-ed different types of communication (e.g., passive, aggressive, passive-aggressive, assertive)
- Prompt group to reflect on styles of communication they have defaulted to in various situations
- Review assertiveness key points and strategies to prepare participants for small group activity
- Break participants into groups of 2-3 to talk through a situation in their life where they may want to be more assertive. What strategies might you try? What barriers could get in the way? (~10 minutes)
- Return to main room to discuss briefly

Topic 3: Mountain meditation

- Briefly discuss

Practice (page 40)

- Review Practice: assertiveness, meditation recording

Wrap up

- Answer any questions
- Remind them to connect to group the same way we did today – with this zoom link

Session 6

Check-In (allow up to 30 minutes)

- Briefly say hello to participants and then put them into a breakout room (or multiple rooms depending on group size) to check in with each other
- Bring participants back to the large group room, ask them how they're doing this week, to share about their Practice (mountain meditation, assertive communication), and anything else that came up during the breakout room check in.

Topic 1: Chronic Illness and Loneliness

- Discuss how chronic illness and impact social connection
- Foster discussion regarding how social connection has changed due to illness and thoughts that may prevent interaction (may refer back to de-fusion session)
- Discuss loneliness as the problem and illness as a barrier

Break (5 min)

Topic 2: Improve quantity and quality of relationships

- Review importance of quality social support
- Review how to develop and nurture a support system and invite discussion
- Review setting limits in relationships and invite discussion
- Ask group members what has been helpful for their friends and family to do

Topic 3: Resources

- Briefly orient participants to the activity ideas and resources sheet. We won't go through together in the interest of time, but they are encouraged to review on their own.

Activity: Meditation (page 47)

- Introduce loving kindness meditation: LKM is a mindfulness based meditation that helps to cultivate feelings of compassion, kindness, and love. We will start by sending loving kindness to ourselves, then someone who means a lot to us, then someone who is an acquaintance, and end with sending loving kindness to as many being as we can. Skip the disliked person portion.
- Facilitate meditation
- Discuss experience. May ask participants if they would try LKM for someone they dislike. Orient them to recording for practice.

Practice (page 50)

- Develop goal to increase social connection; practice LKM or other mindfulness exercises.

Wrap up

- Answer any questions
- Remind them to connect to group the same way we did today – with this zoom link

Session 7

Check-In (allow up to 30 minutes)

- Briefly say hello to participants and then put them into a breakout room (or multiple rooms depending on group size) to check in with each other
- Bring participants back to the large group room to check in with facilitators as well
 - Check-in about topics from last week, including social support and LKM.
 - Begin to prepare participants that we only have 3 sessions left
 - Personal reflection on participation
 - How we can facilitate group
 - Prep for feedback last session

Topic 1: What is medical trauma (15 min)

- Prepare participants that we will be talking a bit about trauma today and remind participants that we want to avoid sharing details of trauma so not to trigger other group members
- Provide education regarding medical trauma with a few brief examples.
- Provide education about symptoms of PTSD and how to cope with medical trauma

Break

Topic 2: Resilience

- Ask participants to take turns reading the quotes and reflecting on their meaning
- Discuss that resilience is not a trait but something that can be learned. It is not an absence of pain or difficulty.
- Review what resilience involves and ways to build resilience. Can foster discussion here if time.

Activity: Gift Giving

- Break participants into pairs
- Have each person think of something the other may want and sketch that item.
- Each person will share their “gift” with the other
- Bring back to larger room and discuss activity (e.g., what was it like to receive the “gift” ; are there lesson from this activity that we can apply to daily life?)

Activity: Meditation (page 56)

- Facilitate gratitude meditation
- Briefly discuss

Practice (page 58)

- Review resilience and gratitude exercise
- Orient to a variety of gratitude meditations for them to try

Wrap up

- Answer any questions

- Remind them to connect to group the same way we did today – with this zoom link

Session 8

Check-In (allow up to 30 minutes)

- Briefly say hello to participants and then put them into a breakout room (or multiple rooms depending on group size) to check in with each other
- Bring participants back to the large group room
 - How is everyone?
 - Review Practice (gratitude activity and meditations)
- Review page 58 to orient group to today's session topic

Topic 1: Meaning Centered Living (page 59)

- Share screen and review, have participants take turns reading
- What do you all think of these quotes? Do you agree? Do you disagree?
- Terms like meaning and purpose can be vague; what does meaning mean to you?
 - Review definitions on page 59

Break

Activity: Meaningful Moments Exercise (page 61)

- Sources of meaning
- Create 2-3 smaller groups, place them in breakout rooms, and prompt participants to discuss the activity on page 61
- Bring larger group back together for discussion

Mindfulness Exercise

- Self-love with chronic illness guided meditation recording

Practice (page 62)

- Review the values clarification and values mall exercises/Practice from session 2 (page 15)
- Have any of your thoughts or beliefs regarding your values changed since the beginning of group? How do you feel now compared to then regarding your ability to pursue or re-discover these values?

Session 9

Check-In

- Briefly say hello to participants and then put them into a breakout room (or multiple rooms depending on group size) to check in with each other
- Bring participants back to the large group room
 - How is everyone doing today? Thoughts about last week's session?
 - Review Practice (visualization, values)
 - What topics came up in the breakout room?
- Review page 64 to orient group

Topic 1: Reflect on Group

- What did you like about group?
- What was most helpful?
- What was least helpful?
- What topics would you have liked to discuss that we didn't cover?
- What did you learn from group?

Topic 2: What Comes Next?

- Inform participants that there are other groups they could join if they are interested (CBT, mindfulness, etc.)
- Review page 65
 - Ask participants their biggest take away from group and what they'd like to continue doing now that it's over

Goodbyes

- Tell participants that we would like them to complete a survey before exiting. We will say our goodbyes, then click on the link before leaving group. Once the survey is completed, they can feel free to leave.
- Thank them for their participation
- Tell them what you have learned/how you have benefitted from being a part of the group
- Allow participants to exchange contact information if they'd like. They can choose to share phone numbers, email addresses, etc. either by telling each other or typing it in the chat.

Surveys

- Sent link in zoom chat and/or via MHC message