

SGF Resource Discussion Guide

Myotonic Dystrophy and Mental Health Handbook

1. What is the purpose of this discussion guide?
 - a. Use this discussion guide to lead a 15-20 minute discussion about the resource “Myotonic Dystrophy and Mental Health Handbook” with your support group.
 - b. As an SGF, you are not expected to be an expert, but you do act as a liaison for the community and MDF’s resources. This means you are in a great position to share information and resources with the community and start a conversation around specific topics.

2. Do’s and Don’ts of Resource Discussion:

Do’s	Don’ts
Tell everyone to talk to their doctor’s before changing anything pertaining to their health	Suggest folks change their habits without consulting with their care team
Allow community members to share their personal experiences	Allow community members to suggest other people follow their habits
Share MDF resources	Share unvetted resources or research
Allow community members to recommend clinicians who have helped them with this issue	

3. How to use this discussion guide:
 - a. Before your meeting
 - i. Send your group an email explaining that you will be discussing the MDF resource Myotonic Dystrophy and Mental Health Handbook: https://www.myotonic.org/sites/default/files/2025-03/MDF_Mental-Health-Handbook_3-2025.pdf
 - ii. Share the resource and encourage them to look through it before your next group meeting.

- iii. **Note:** As we learned in SGF training from Give an Hour- it is not the responsibility for an SGF to treat someone who is struggling with their mental health or experiencing anxiety/depression etc. Instead, you are invited to listen and support by empowering group members to seek clinical help when needed, encourage self-awareness, and encourage the use of MDF resources, creating meaningful connection and community. Use reflective listening and empathetic statements to make community members feel heard and seen.
 - 1. You may consider reviewing this SGF training resource before your support group:
https://www.myotonic.org/sites/default/files/2024-05/Rare-Care-Workshop_2024-MDF-SGF.pdf
- b. During your meeting/discussion
 - i. Remind everyone to speak with their doctors or therapists to ask specific questions, and that no one in your group is there as a mental health practitioner and therefore cannot give advice. Remind everyone that the purpose of this discussion is to learn from each other, but they should always speak with their care team to get medical advice.
 - ii. Remind everyone that talking about mental health can be vulnerable, but MDF's support groups are a safe space and confidential. No one will share the stories told during Support Groups.
 - iii. Ask questions: Here are some sample questions to start a discussion on "Myotonic Dystrophy and Mental Health Handbook"
 - 1. What was your favorite part of the Myotonic Dystrophy and Mental Health Handbook?
 - 2. Was anything in the Handbook surprising to you? Why?
 - 3. What motivates you to think about your mental health?
 - 4. What adaptive behaviors do you use to maintain independence?(Page 8)
 - 5. What recommendations from the guidebook do you already use?What are you interested in trying? (page 16)
 - a. Ask about: breathing techniques, meditation, autogenetic training, progressive muscle relaxation, respite care

6. Are you interested in trying therapy?
 - a. What is preventing you?
 - b. **Note:** if the reason is finances, you can encourage community members to find a therapist covered by their insurance at [psychologytoday.com](https://www.psychologytoday.com), or reach out to info@myotonic.org for support in finding help.
 - iv. Be prepared to pull up the guide and share your screen if directly referencing the guide proves helpful.
4. At the end of your discussion or after your meeting
 - a. Thank everyone for sharing their experiences
 - b. If these topics come up, you may consider sharing these additional
 - i. An Introduction to Mindfulness and Guided Meditation: <https://www.myotonic.org/digital-academy/introduction-mindfulness-guided-meditation>
 - ii. Emotional and Mental Health Resources by State (from partner organization Global Genes) <https://globalgenes.org/blog/finding-support-a-compilation-of-emotional-and-mental-health-resources-in-the-united-states/>
 - iii. DM and Mental Health: Managing Anxiety, Depression and Other Symptoms: <https://www.myotonic.org/digital-academy/dm-and-mental-health-managing-anxiety-depression-and-other-symptoms>
 - iv. Strategies for Managing Disease Progression: <https://www.myotonic.org/digital-academy/dr-dixon-strategies-managing-progression-2018-mdf-annual-conference>
 - v. Find a Therapist: <https://www.psychologytoday.com/us>
 1. Encourage community members to include their insurance, and search for someone with experience supporting those with Rare Disease!