

Support Group Facilitator Resource Discussion Guide

Exercise Guide for People Living with Myotonic Dystrophy

1. What is the purpose of this discussion guide?
 - a. Use this discussion guide to lead a 15-20 minute discussion about the resource: “Exercise Guide for People Living with Myotonic Dystrophy:” 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 doctors/physical therapists before changing anything pertaining to their health or movement practices	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 “Exercise Guide for People Living with Myotonic Dystrophy:” https://www.myotonic.org/sites/default/files/pages/files/MDF_Exercise-Guide-for-the-Community_1_21.pdf

- ii. You may also consider sharing the Infographic:
https://www.myotonic.org/sites/default/files/2024-07/MDF_Exercising-with-Myotonic-Dystrophy_Infographic.pdf
 - iii. Share the resource and encourage them to look through it before your next group meeting.
- b. During your meeting/discussion
- i. Remind everyone to speak with their doctors or physical therapists to ask specific questions, and that no one in your group is there as a doctor 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. Ask questions, here are some sample questions to start a discussion on “Exercise Guide for People Living with Myotonic Dystrophy”
 - 1. What was your favorite part of the Exercise Guide for People Living with Myotonic Dystrophy
 - 2. Did you know about the four pillars of exercise for people living with DM?
 - 3. Which pillar of movement do you practice the most?
 - a. Which pillar of movement would you like to work more on?
 - 4. What motivates you to exercise?
 - 5. What is your regular movement practice?
 - a. Note: this will be different for everyone, some folks may say they stretch in bed every morning, and some may go on a one mile walk. Be sure to support all different types of answers, and thank community members for sharing!
 - 6. Did anyone participate in Myotonic Dystrophy In Motion Awareness Month this July? What was that like?
 - 7. Would you be interested in doing one of the exercise videos (page 14) together as a support group?
 - a. If so, you can choose to do it in this meeting, or plan to do it next time!
 - 8. What questions do you still have and want to bring to your physical therapist?
 - iii. 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. Share the Exercise Guide for People Living with Myotonic Dystrophy: https://www.myotonic.org/sites/default/files/pages/files/MDF_Exercise-Guide-for-the-Community_1_21.pdf
 - c. Share the Exercise Infographic: https://www.myotonic.org/sites/default/files/2024-07/MDF_Exercise-with-Myotonic-Dystrophy_Infographic.pdf
 - d. Share other related MDF webinars:
 - i. Exercises for everyday life: <https://www.myotonic.org/digital-academy/exercises-everyday-life-2024-motion-awareness-month>
 - ii. Nature and Breathwork: <https://www.myotonic.org/benefits-nature-breathwork-2024-motion-awareness-month>
 - iii. Stump the Doctor and Community Panel: <https://www.myotonic.org/digital-academy/stump-doctor-community-panel-2024-motion-awareness-month>
 - iv. Exercise and Myotonic Dystrophy: <https://www.myotonic.org/digital-academy/exercise-myotonic-dystrophy-2024-mdf-regional-conference-gainesville-fl>
 - v. Ask the Expert: <https://www.myotonic.org/digital-academy/ask-expert-exercise-movement>