SGF Resource Discussion Guide

Myotonic Dystrophy and the Heart: A Community Guide

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 the Heart: A Community Guide” 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 the Heart: A Community Guide”. https://www.myotonic.org/sites/default/files/2024-07/MDF_Heart-Community-Guide_7-2024.pdf
      ii. 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 cardiologist to ask specific questions, and that no one in your group is a doctor and therefore cannot give advice.
    ii. 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.
    iii. Ask questions, here are some sample questions to start a discussion on “Myotonic Dystrophy and the Heart: A community Guide”
        1. What was your favorite part of Myotonic Dystrophy and the Heart: A community Guide?
        2. Has anyone here had an Electrocardiogram or echocardiogram before? What was that like?
        3. Does anyone with a pacemaker or ICD want to share their experience?
        4. (For Regional Support Groups) Who is your cardiologist?
        5. What do you do to support your heart health?
            a. Ex: exercise, regular testing, pay attention to my symptoms, staying informed with new research.
        6. What questions do you still have and want to bring to your cardiologist?
    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. Share the Myotonic Dystrophy and the Heart: A community Guide https://www.myotonic.org/sites/default/files/2024-07/MDF_Heart-Community-Guide_7-2024.pdf
    c. Share other related MDF resources:
    i. Ask the Expert: https://www.myotonic.org/digital-academy/ask-expert-myotonic-dystrophy-heart
    ii. DM1: https://www.myotonic.org/sites/default/files/pages/files/MDF_Consensus-basedCareRecsAdultsDM1_Cardiologists_1_21.pdf