

SGF Resource Discussion Guide

Practical Advice for Anesthesia for Individuals with Myotonic Dystrophy & their Families

1. What is the purpose of this discussion guide?
 - a. Use this discussion guide to lead a 15-20 minute discussion about the resource “Practical Advice for Anesthesia for Individuals with Myotonic Dystrophy and Their Families” with your support group.
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.
 - b.

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 “Practical Advice for Anesthesia for Individuals with Myotonic Dystrophy and Their Families”.
https://www.myotonic.org/sites/default/files/2024-11/MDF_Anesthesia-Community-Guide_11-2024.pdf
 - ii. Share the resource and encourage them to look through it before your next group meeting.
 - iii. **Note:** make sure your group understands that this is the community facing guide, which are different than the Practical Suggestions for the Anesthetic Management of a Myotonic Dystrophy Patient, which is aimed at doctors.
 - b. During your meeting/discussion

- i. Remind everyone to speak with their anesthesiologist 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 “Practical Advice for Anesthesia for Individuals with Myotonic Dystrophy and Their Families”
 - 1. What was your favorite part of Practical Advice for Anesthesia for Individuals with Myotonic Dystrophy and Their Families?
 - 2. Are you all familiar with the Practical Suggestions for the Anesthetic Management of a Myotonic Dystrophy Patient for your doctors?
 - 3. Does anyone have a story of a time they needed to advocate for their doctors to review MDF’s Anesthesia Guidelines?
 - 4. (for regional support groups) Who is your anesthesiologist? What questions do you still have and want to bring to your anesthesiologist?
 - 5. anesthesiologist?
 - 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 additional resources:
 - i. Anesthesia Guidelines:
https://www.myotonic.org/sites/default/files/pages/files/MDF_PracticalSuggestionsDM1_Anesthesia2_17_21.pdf
 - ii. Anesthesia Quick Reference:
https://www.myotonic.org/sites/default/files/pages/files/MDF_PracticalConsiderationsAnesthesiaQG_1_21.pdf