



**Myotonic
Dystrophy**
FOUNDATION

www.myotonic.org

Support Group Facilitator Handbook





Myotonic Dystrophy Foundation

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Welcome

Dear MDF Support Group Facilitators,

I am deeply grateful for your ongoing leadership as a Support Group Facilitator (SGF) and community leader. Your commitment to the myotonic dystrophy (DM) community, and the Myotonic Dystrophy Foundation (MDF), is truly inspiring and I hope you know what a significant difference you make in the lives of our team, your peers, and the extended DM ecosystem.

As an SGF you are often the first contact a new community member has with MDF. It is evident that you hold this responsibility in high regard; community members regularly call and email our team to let us know how grateful they are to have you in their lives and what a positive difference you have made for them. The time and attention you dedicate to creating meaningful support group sessions, and ensuring families have the life-saving resources needed, is extraordinary – and I know it isn't always easy! Your ability to honor and support our community's lived experiences is part of what makes MDF the strong patient advocacy organization the world recognizes today. Thank you for helping us keep our community at the center of our decisions.

Time and time again, I am impressed with the diverse ways you engage as leaders. Not only do you maintain a regular schedule of amazing support groups, but you also support our wider programming and initiatives by reviewing new resources, serving on numerous committees, calling to welcome first-time event attendees, activating your personal networks, helping evaluate programming, advocating for change, and always, always, ensuring the voice of our community is present. Your integrity, dependability, empathy, and kindness are what remind MDF we can count on you.

As MDF community programming continues to grow stronger, this year we will have 45 SGFs, 30 Support Groups, and 5 Facebook Groups. Whether this is your first time as an SGF or you have been supporting our community in this capacity for years, the handbook that follows is dedicated to you.

I hope you know, and believe, that our community is stronger because of you. You work every day to help lift people's spirits, empower them with knowledge and connection, and ensure they know they are not alone. YOU CHANGE PEOPLE'S LIVES. MDF's work would not be possible without you and certainly not without your resilience and optimism. I simply do not have the proper words to express my true appreciation and gratitude for all you have done and continue to do to improve the quality of life of our families and change the future of this disease.

It is an honor and privilege to work with each of you. Thank you for your continued professionalism, your compassion, and perhaps most importantly, your partnership.

With all my respect and love,



Tanya Stevenson

Tanya Stevenson, EdD, MPH
Chief Executive Officer

Myotonic Dystrophy Foundation Overview

About MDF

The Myotonic Dystrophy Foundation (MDF) is the leading global advocate helping patients and families navigate the myotonic dystrophy (DM) disease process, and is often the first resource contacted by newly-diagnosed patients, their families, their social workers and their physicians around the world. For many international patients, the Myotonic Dystrophy Foundation is often the only resource they are able to locate, and MDF has provided assistance and support for people living with DM in more than 139 countries around the world.

Currently tens of thousands of people living with myotonic dystrophy, their families & friends make up the Myotonic Dystrophy Foundation community.

Our Vision

We envision a world with treatments and a cure for myotonic dystrophy.

Our Mission

The mission of the Myotonic Dystrophy Foundation is Community, Care, and a Cure.

- We support and connect the myotonic dystrophy **community**.
- We provide resources and advocate for **care**.
- We accelerate research toward treatments and a **cure**.



Our Team



Tanya Stevenson, EdD, MPH
Chief Executive Officer



Andy Rohrwasser, PhD, MBA
Chief Scientific Officer



Kate Beck
Director of Development



Mindy Buchanan
Director of Programs



Kleed Cumming
Director of Communications
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Lucie Shiffman
Sr. Manager of Community Engagement



Emily Romney, MPA
Community Education Manager



Nadine Skinner, PhD, MPA
Research Grants Manager



Sofia Olmos, PhD
Myotonic Dystrophy Family
Registry Coordinator

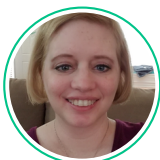


Genevieve Wiegleb
Communications Associate



Renee Smith
Fundraising and Operations Coordinator

Our Consultants



Mindy Kim
Registry Outreach Coordinator



Kevin Brennan
Advocacy Consultant



Ruth Sheldon, MPH, MSW
Health Resources Consultant

MDF Board of Directors



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Chair



Martha Montag-Brown
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Thomas (Tom) McPeck



Robert D. Campagna, MD

MDF Scientific Advisory Committee



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Charles Thornton, MD
University of Rochester



Cynthia Gagnon, MD
Sherbrooke University



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Douglas Kerr, MD, PhD, MBA
Generation Bio



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Guillaume Bassez, MD, PhD
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Kathie Bishop, PhD
Otonomy Inc.



Laura Ranum, PhD
University of Florida



Nicholas E. Johnson, MD, M.Sci
Virginia Commonwealth University



Thomas Cooper, MD
Baylor College of Medicine



Richard Moxley III, MD
Emeritus Member



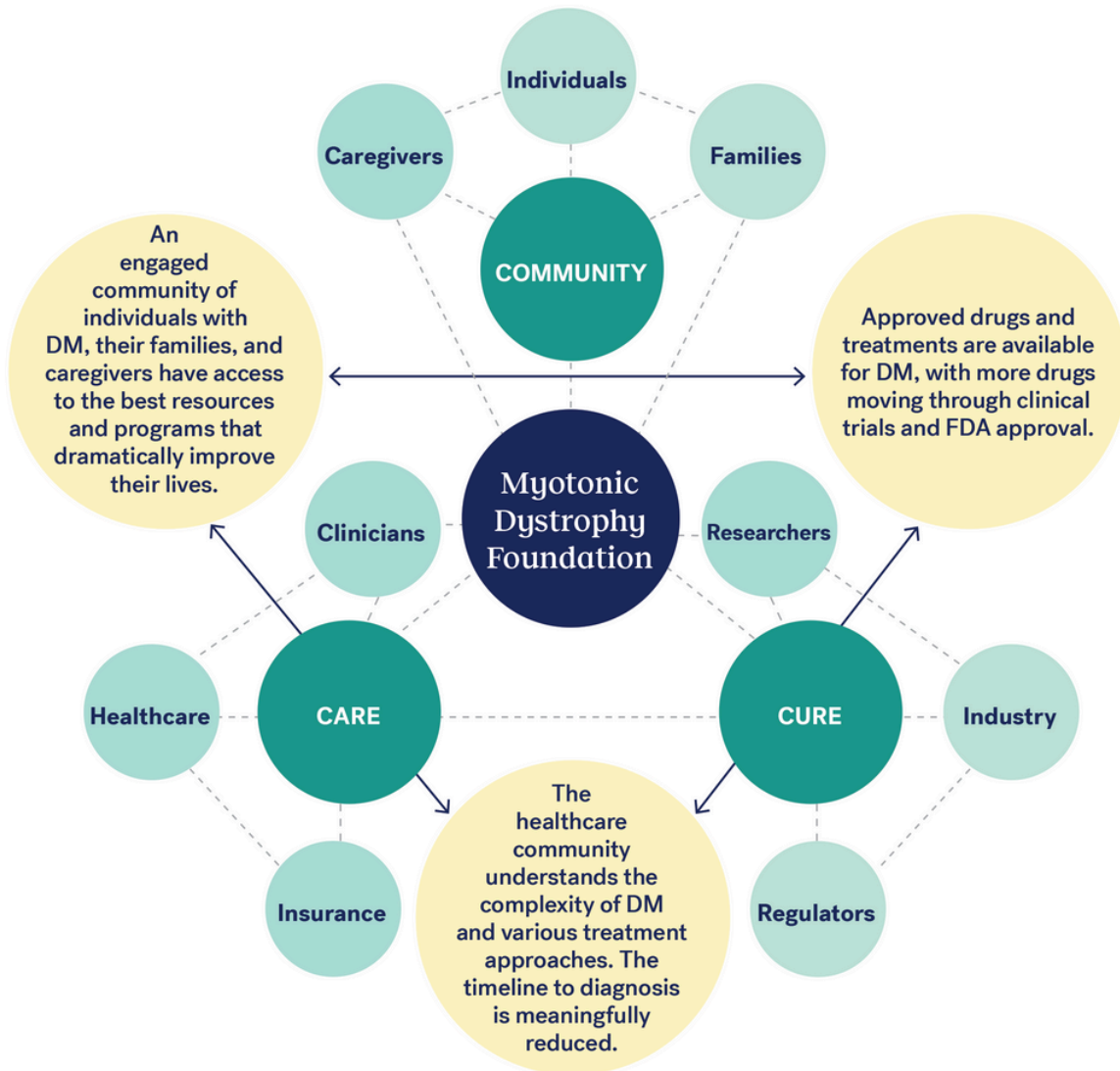
Tetsuo Ashizawa, MD
Emeritus Member

MDF Theory of Change

MDF's Theory of Change connects our mission to our vision. It outlines the logic behind how the Foundation's mission and core activities will produce outputs and outcomes that will bring us closer to our envisioned future where no one is experiencing the negative effects of myotonic dystrophy. Please see the diagram below for a visual representation.

MDF takes a comprehensive and collaborative approach. Through direct services, education, and advocacy, we promote a vibrant and connected community, increase access to appropriate healthcare and crucial resources, and eliminate barriers to drug development. This approach leads to reduced time to diagnosis, improved clinical care, higher quality of life, advancements in research and approved drugs, and ultimately, a cure.

We envision a world with treatments and a cure for myotonic dystrophy.



We support and connect the myotonic dystrophy community, provide resources and advocate for care, and accelerate research toward treatments and a cure.

Support Group Facilitator Overview & Role

The SGF team plays a vital leadership role within the DM community. SGFs are volunteer community leaders who receive training and support from the MDF to create spaces for those living with DM, and their caregivers to confidentially share their experiences, learn from others impacted by DM, and access resources and information to help improve quality of life.

SGF's provide leadership for support groups that are sponsored by the MDF. SGFs make a two-year commitment and agree to follow the SGF roles, responsibilities, and support group policies provided by the MDF. All SGFs must host a minimum of four support groups per year to remain in the position.

Requirements & Responsibilities

Support Group Management:

- Collaborates with support group co-facilitator (if you have one).
- Coordinates support group meeting logistics either in-person or virtually, including frequency of meetings and meeting date.
 - For in-person: identifies appropriate location, secures meeting fees, and procures snacks and/or refreshments.
 - For virtual meeting: works with MDF to establish Zoom
- Ensures MDF has correct meeting dates and times set up for promotion and events calendar.
- Communicates meeting date and time to group participants either via phone or email.
- Attends and leads support group meetings as scheduled.
- If meeting guests are desired, generates topic ideas for support group meetings and recruits, or works with MDF to recruit guest speakers.
- Raise awareness of current MDF educational initiatives, including resources available at www.myotonic.org, special events, and conferences.



Support Group Facilitator Overview & Role

Communication with MDF:

- Attend quarterly one-on-one meetings with the Sr. Manager of Community Engagement.
- Provide MDF with up to date meeting information such as date and time at minimum once every six months.
- Communicate special speaker or topics 3 weeks in advance of meeting date.
- Communicate special and/or difficult situations or incidents which arise during a support group meeting within 48 hours.
- Document support group meeting via the SGF meeting form (if your group does not have Zoom registration).
- Should an SGF plan to host a group in a private home or business, he/she/they must first seek MDF's approval, as well as provide documentation of insurance.
- Speakers secured by SGFs should be shared with MDF prior to confirming their speaking engagement for the group.

Participation in Training:

- Attend monthly SGF virtual meeting, at least quarterly.
- Attend, either in-person or virtually, Annual SGF training.

Leave:

It is recognized that SGF's may need to step away from their role due to personal situations, either temporarily or permanently. In this case, SGF's should contact the Senior Manager of Community Engagement as soon as this need arises so that a smooth transition may occur for both the SGF and their support group participants.

Facebook Groups:

- SGFs should not create new Facebook Groups related to DM.
- SGFs are welcome to maintain any groups created prior to joining MDF as an SGF.
 - SGFs should not promote these groups within MDF Support Groups.
 - SGF's should indicate their non-MDF groups are not part of or endorsed by MDF on their description page.

Support for YOU

MDF provides the SGFs with resources and training as well as channels for communicating, building and maintaining the support groups. The SGFs are supported by the entire MDF staff and more specifically by the Senior Manager of Community Engagement.



Lucie Shiffman

Sr. Manager of Community Engagement

Lucie.Shiffman@myotonic.org

✓ **Initial Training**

To best serve our community, all SGFs must attend the annual SGF training. This is a comprehensive weekend training developed by MDF staff to support the SGFs in their mission. The training is held in person with meals, transportation, and lodging provided for the SGF by MDF. For those not able to attend in person, a virtual option is available.

✓ **Monthly SGF Meeting**

A virtual SGF meeting is held each month. Meetings are one-hour in length unless announced in advance. Meetings include all SGFs and are run by the Senior Manager of Community Engagement. Other MDF staff members may attend the meeting, as needed.

All meetings will include MDF announcements, procedural updates for SGFs, and an opportunity for SGF discussion. Any special training topics will be announced in advance. SGFs may send new agenda items to MDF in advance.

✓ **In-Person Meeting Reimbursements**

MDF may provide reimbursements to SGFs for the purchase of healthy snacks and refreshments, low cost meeting space, and other incidentals for in-person meetings.

✓ **Dedicated SGF Webpage**

MDF provides a confidential webpage dedicated to SGFs. This page houses forms and other information you need to support your attendees. Past trainings are available online through this page. www.myotonic.org/sgf-resources



Support for YOU

✔ Emotional Wellbeing & Support

While facilitating a Community Group can be very rewarding, it is important to pay attention to your self-care needs, and ensure you are emotionally and physically prepared to support others. MDF has a licensed clinical social worker available on-call for SGF's.

The social worker is available to address issues related to crisis intervention, or to provide assistance with supporting group members emotionally. Please note: the MDF licensed clinical social worker is only available to the SGF's: support group participants should not be given the social worker's contact information. On-call contact information is available through the Senior Manager of Community Engagement.



Vanessa Zinke, LCSW

SGF Monthly Support Group Facilitator

On-Call Support

Non-Urgent: vanessazinkelcsw@gmail.com

Urgent: call or text: 646-300-3089

✔ Zoom Account for Virtual Support Groups

MDF provides on-line and hybrid support groups with a licensed Zoom account for support group meetings. Training by MDF staff on using Zoom for on-line support groups is provided and is available on an on-going basis via phone or email. SGFs may also choose to review live and recorded trainings on the SGF webpage.

SGFs must either institute Zoom registration for their groups or provide post-meeting forms.

✔ @sgf.myotonic.org Email Address

MDF provides SGFs with an MDF email account to use when communicating with their support groups. This email address will be connected with the support group Zoom account, so it should be the main email address used for all group communication. Please see "Establishing a Support Group" for more information. Example: ChuckH@sgf.myotonic.org.

Note: Email addresses are NOT case sensitive, so chuckh@sgf.myotonic.org also works!

Support for YOU

✔ Business Cards

MDF provides SGFs with MDF business cards. These cards can be used at conferences, or other engagements where you are representing MDF or participating as a community member. Personal or other non-MDF business cards should not be used for support group or MDF-related communication.



✔ Attending MDF Conferences

MDF provides reimbursable travel stipends (\$500) as well as coverage for hotel costs for SGFs to attend the Annual or Regional MDF Conference.

As a leader in the community, it is important to attend the Annual Conference or Regional Conferences if you are able to. MDF is dedicated to supporting your attendance.

Establishing an MDF Support Group

✔ Establishing Your Group Culture

While MDF Support Groups take a variety of approaches, all are either topic and/or community-building (support) based. These approaches depend on the needs and interests of the SGFs and their group members. The needs and interests of groups are likely to differ somewhat based on the characteristics of group members. For instances, are most members affected by DM or caregivers? Some of the ways these groups may differ include:

Content:

Some groups may focus on bringing in clinical experts in DM to cover disease specific information. Others may bring in more ancillary providers or non-medical experts to provide overviews of resources that address living with DM, such as diet and exercise. Still others, may wish to mix and match the styles above.

Format:

Some groups may prefer meeting in person and some are virtual. Some will be hybrid, taking advantage of both.

Even within these different formats, SGFs have an opportunity to establish a group culture. Some groups may want to pose a question out to the members and have everyone answer (or everyone who feels comfortable) while other groups may have a more organic discussion-based format where attendees share their latest experiences.

Pro Tip!

Use the worksheet to determine the culture of your group.



Establishing an MDF Support Group

✔ Meeting Frequency, Date and Time

Meetings may be held quarterly, bi-monthly, or monthly. When establishing a new support group, it is often recommended to begin with quarterly meetings and then to proceed with bi-monthly or monthly meetings as the support group community grows. Meeting times should consider the traditional work-day schedules. If leading a support group that includes multiple time zones, a time should be chosen that will be most available across all the time zones.

When selecting the frequency, meeting date, and time of the meeting, SGFs should consult their personal calendar one-year in advance to ensure that they would be available (barring any emergency situations) to lead the meetings.

Length:

It is recommended that on-line and in-person meetings are one to two hours in duration. Meetings should not last more than two hours.

✔ Building the Group Community

There's no wrong way to get the word out about your group! We know how difficult it can be to motivate folks to attend a support group. And MDF is here to help you!

MDF Will Promote Your Group By:

- Posting about your group across MDF social media accounts.
- Providing meeting information on www.myotonic.org calendar of events as well as the Support Group page.
- Emailing one-week in advance of the meeting.
- Sharing in the monthly Dispatch
- Sharing through Warmline interactions.

Pro Tip!

Seek out feedback through snap polls and MDF evaluations to better understand the needs of your group



Establishing an MDF Support Group

You Can Promote Your Group By:

- Sending email reminders to participants the week of the meeting. Remind them of date/time, and if you have any guest speakers.
- Post to social media
 - Share or like posts from MDF or create your own!
- If you have Zoom registration: make sure to trigger attendees' join-link on the day of your meeting.
- Put flyers up at your local doctor/clinic.
- Share MDF-branded Support Group materials with your providers and encourage them to refer their patients to your group.
- Attend MDF or other conferences and share your group information.



Pro Tip!

Highlighting an expert speaker can entice people to join your group for the first time!



Need a refresher on Zoom Registration and Sending Reminders?

Watch the Zoom Training for MDF Support Group Facilitators!

Virtual Support Group Meetings

✔ MDF Zoom Account

On-line support group meetings will be held using the platform “Zoom”. Each on-line support group is provided with a licensed MDF Zoom account. On-line support groups should only be held using the licensed MDF Zoom account, rather than a personal account. SGF’s should not share their Zoom passwords with anyone.

Zoom Hosts:

Zoom Hosts are the primary holder of the Zoom meetings for your group.

Hosts must open meeting from the Zoom app or website.

Zoom Hosts Can:

- Launch a support group meeting from inside Zoom.
- Send an email reminder with the attendee join-link for registered attendees.
- Make someone else the host or co-host once the meeting has started.
- Establish and monitor breakout rooms.
- Let people in from the waiting room.
- Schedule additional meetings in Zoom.
- Rename attendees.
- Launch polls.



Virtual Support Group Meetings

Zoom Co-Hosts:

Zoom Co-Hosts are the secondary of the Zoom meetings for your group.

Co-Hosts must join or launch the meeting from the unique link sent to their email. This is different than the link sent to attendees.

Zoom Co-Hosts Can:

- Launch a support group meeting from their unique link.
- Make someone else the host or co-host once the meeting has started.
- Establish and monitor breakout rooms.
- Let people in from the waiting room.
- Rename attendees.
- Launch polls.



Pro Tips!

- Ensure there are no last minute updates or technical difficulties with Zoom
 - **Hosts:** Login to Zoom at least 10 minutes before the meeting
 - **Co-Hosts:** Click on your unique link at least 10 minutes before the meeting
- Identify who will take lead on: (feel free to alternate!)
 - Introductions
 - Admitting people into the Zoom room
 - Verifying DM diagnosis/status
 - Monitor the chat

In-Person/Hybrid Support Group Meetings

✔ Setting Up Your In-Person Meeting

All meeting locations are ideally available for free or donated. Potential meeting locations include hospital conference rooms, public libraries, faith-based institutions, and non-profit organizations with meeting room space. In-person support groups should not be held in a private home, business, or domicile.

Location:

If holding a regular or occasional in-person meeting, ensure the following standards are met:

- Meeting room in a public location that is completely ADA accessible
- Access to an ADA compliant restroom close to the meeting room
- A well-lit room that is easy to move about in an accessible device and has reasonably comfortable chairs
- Access to accessible parking for cars and vans
- Easy access to parking that is walkable for those not using accessible permits
- Sufficient lighting in parking lot or garage for evening meetings
- Easy to find location in a central area



In-Person/Hybrid Support Group Meetings

Before Your Meeting:

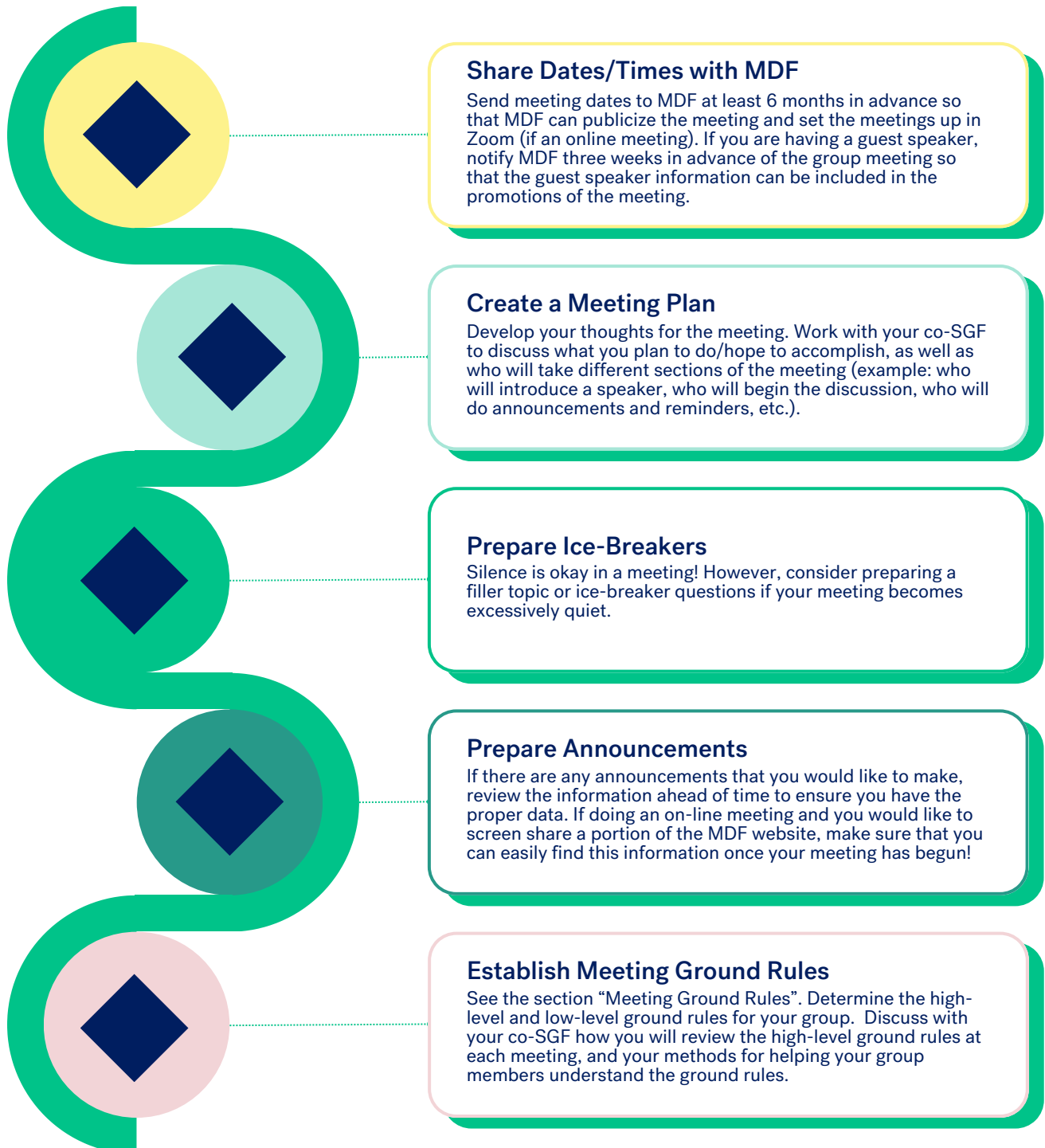
When meeting in person, it's important to ensure you have covered all the necessary basis for your group to feel comfortable and safe.

- Secure the meeting location. Make sure you have a written agreement with the facility that spells out all of the dates and times for your group meetings.
 - Note: if this includes a fee, MDF should approve before you agree to the location.
- Determine if there are rules required by the meeting facility. SGFs should review any pertinent facility rules with the participants in your group to ensure everyone understands the expectations.
- Notify MDF staff with the address and meeting dates of your support group meetings at least one month prior to the first meeting
 - Include information about directions and parking
- If having a guest speaker, ensure they have the facility name, directions, your or your co-host's contact information, and the date and time of the meeting.
- Arrive 15-30 minutes early to set up the room, meet the speaker, and station a volunteer or co-facilitator to help participants find the meeting space.
- If bringing light refreshments, ensure they are dysphagia-friendly. Participants should not be charged for food. You may seek reimbursement for refreshments served at your in-person group.
- Consider bringing the following supplies:
 - Box of tissues.
 - Hand sanitizer.
 - Notepads & pens.
 - Disposable masks.
 - If serving refreshments, be sure to bring cups/plates/napkins and items to clean up.
- End your meeting on time! Ensure you end early enough you have time to clean before departing.

Meeting Best Practices

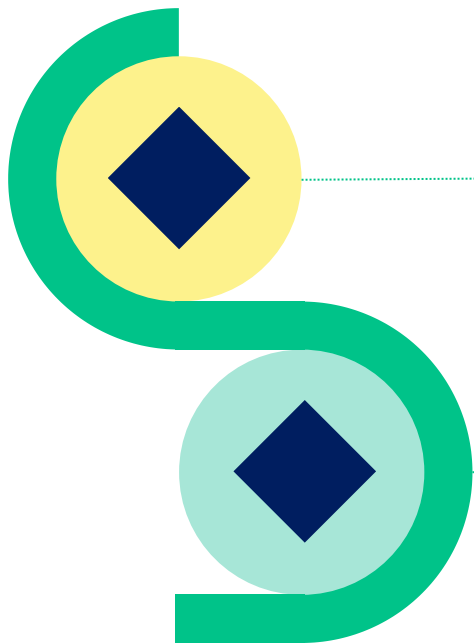
✓ Before the Meeting

There's not one way to conduct an MDF Support Group. However, these are some useful tips and tricks for keeping organized and ensure your group runs smoothly.



Meeting Best Practices

✓ Before the Meeting Continued



Prepare Questions for Speaker

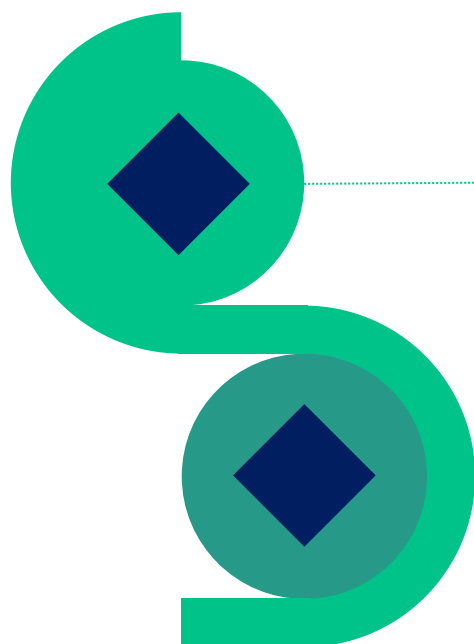
If you'll be having a guest speaker, write out possible questions for them just in case the support group participants don't have any questions for the speaker.

Send Meeting Reminders/Trigger Zoom Join-Link Email

Email regular meeting participants both the week before and the day of the meeting with meeting information and registration information, if the meeting is on-line.

✓ During the Meeting

There's not one way to conduct an MDF Support Group. However, these are some useful tips and tricks for keeping organized and ensure your group runs smoothly.



Be on Time!

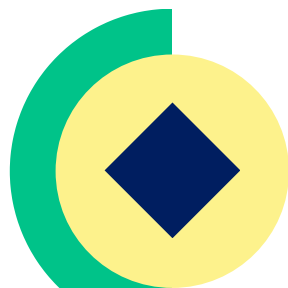
Maintain the designated start and end times for the meeting. Don't penalize the punctual; begin the meeting on time and the latecomers will adjust.

Introduce Everyone

Be sure to introduce yourself and your connection to DM. Invite any group participants to introduce themselves and share their connection. If on-line, invite participants to share in the chat if they would rather not activate their microphone and video. This will help ensure only eligible participants are at the meeting.

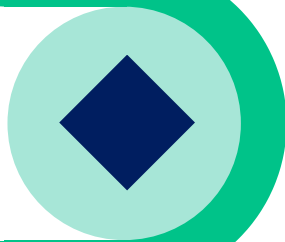
Meeting Best Practices

✓ During the Meeting Continued



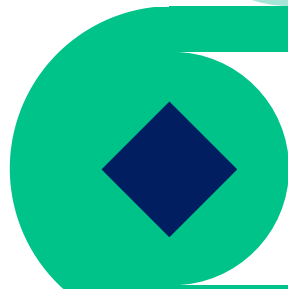
Share the Plan for the Meeting

When new participants know what to expect from a meeting, they may feel more comfortable. For example, if there is a guest speaker at the meeting, SGFs may state that everyone will have 1-2 minutes to introduce themselves, then they'll introduce the guest speaker, and there will be some general announcements in the last few minutes of the meeting. If there is no guest speaker, SGF's could state that everyone will have a chance to introduce themselves, and then they will open the meeting for discussion.



Share High-Level Ground Rules

Setting the tone for the meeting with ground rules can help everyone understand the process and the flow of the meeting. It can also help SGFs ensure that everyone gets a chance to share or talk, as well as enforce rules on interrupting or sharing medical advice. When everyone understands the rules it is easier to follow them.



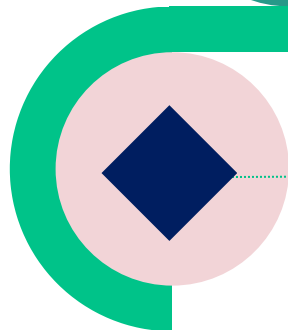
Do Your Best to Stick to the Plan

However, there may be times when due to circumstances beyond your control, you need to shift. It is important to remain flexible and remember that you are there for the group in front of you, and they are looking to you for guidance as the leaders during this meeting.



Everyone Gets to Share

Ensure that no one person dominates the conversation. Gently remind the group that we want to make sure that all in the meeting have an opportunity to share. This is a delicate process and you will become more accustomed and comfortable with gauging if a person needs extra time or is prone to dominating a conversation.



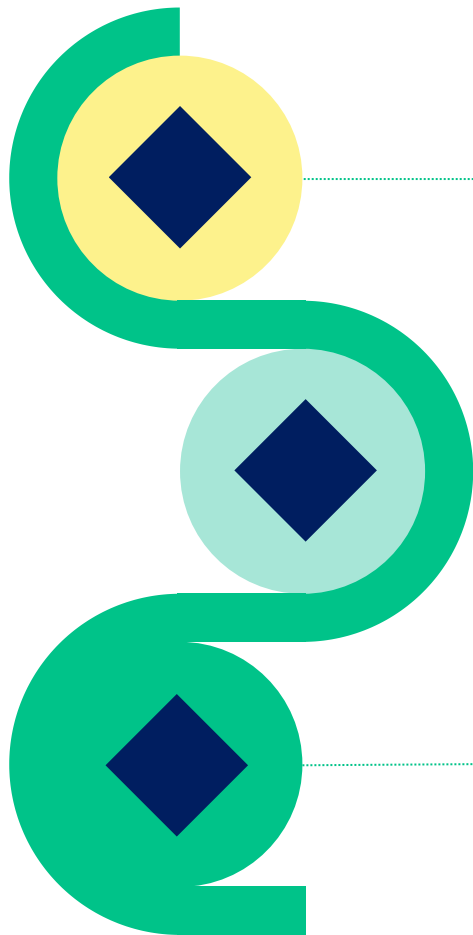
Close the Meeting on Time

Briefly make any important announcements. Bring the meeting to close at the designated end time and thank everyone for coming.

Meeting Best Practices

✓ After the Meeting

In the same way you prepare for your meeting to ensure it runs smoothly, make sure to take the time to review the meeting with your co-facilitator (if you have one) and share with MDF.



Review How Your Meeting Went

Each support group meeting is a new learning opportunity. After each meeting consider whether everyone had an opportunity to share and express him or herself. Evaluate what changes could be made to make the next meeting an even safer and comfortable space.

Complete the SGF Meeting Form

If you do not have Zoom Registration, it is important to share the names and email addresses of your attendees, as well as share the number of attendees you had at each meeting with MDF.

Alert MDF to Special Situations

Reach out to the Senior Manager of Community Engagement with any special situations that you feel need addressed by MDF staff persons.



MDF Support Group Planning Worksheet

Group Name

Virtual/In-Person/Hybrid

Registration

All MDF Support Groups must have some form of registration. There are several options for your group.

Zoom Registration

- If your group is already using Zoom, registration this will be the easiest option.
- Automated features allow you to quickly share join links w/meeting attendees.
- Requires no manual reporting from SGFs.
- Requires no changes to communications

Manual Registration

- SGFs will submit virtual reports to MDF within 24 hours of meeting
- Reports must include for each attendee:
 - First and Last Name
 - Email Address
- If reports are not completed three times within 1-year, Zoom and/or virtual registration will be instituted

What are the benefits for having/keeping my group's Zoom registration?

What are the drawbacks for having/keeping my group's Zoom registration?

Support Group Planning Worksheet

I/We believe _____ is best for my/our group moving forward because:

Group Culture

There is not one perfect way to run an MDF support group. A lot depends on what the feel or culture of the group is, and what the attendees hope to have when they attend. You do not need to decide to do one or the other, but will want to plan options in advance.

Below, you will find questions which aim to help you/and your co-facilitator determine what kind of group is best.

Discussion Groups

Discussion groups primarily focus on popcorn-style group discussions. They can be topic based, or they can be open allowing the group to organically determine the course of the discussion.

Groups which may find this culture to be beneficial include: Happy Hour, JOA Warriors, etc.

Education Groups

Education groups tend to provide a guest speaker early in the meeting, open it to questions, and then allow the expert to depart. This provides a natural topic for the discussion to follow after the expert departs.

Most groups may find this culture to be helpful, especially in recruiting attendees.

Do you envision a support group where members actively participate in open discussions, sharing their experiences & insights without a rigid agenda?

Support Group Planning Worksheet

Are you considering a group dynamic where topics are fluid and emerge organically from member contributions, allowing for spontaneous and engaging discussion?

In shaping the culture of your group are you leaning toward a model where discussions revolve around specific themes or topics, fostering a sense of community around shared interests?

Do you see value in incorporating guest speakers who provide expertise and information to kickstart discussions during the group session?

Are you exploring the idea of integrating expert input into the group meetings, allowing members to engage with professionals and ask questions relevant to their needs?

Support Group Planning Worksheet

In terms of group dynamics, are you aiming for a structure where presentations by guest speakers serve as a springboard for deeper discussion among members?

As you shape the culture of your group, do you prioritize providing opportunities for members to learn from professionals or individuals with specialized knowledge?

Are you considering a format where educational segments led by guest speakers happen before member-led discussions, creating a balanced blend of learning and peer support?

Please share the culture you will fit your group best:

Next Steps:

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Things I/We Need:

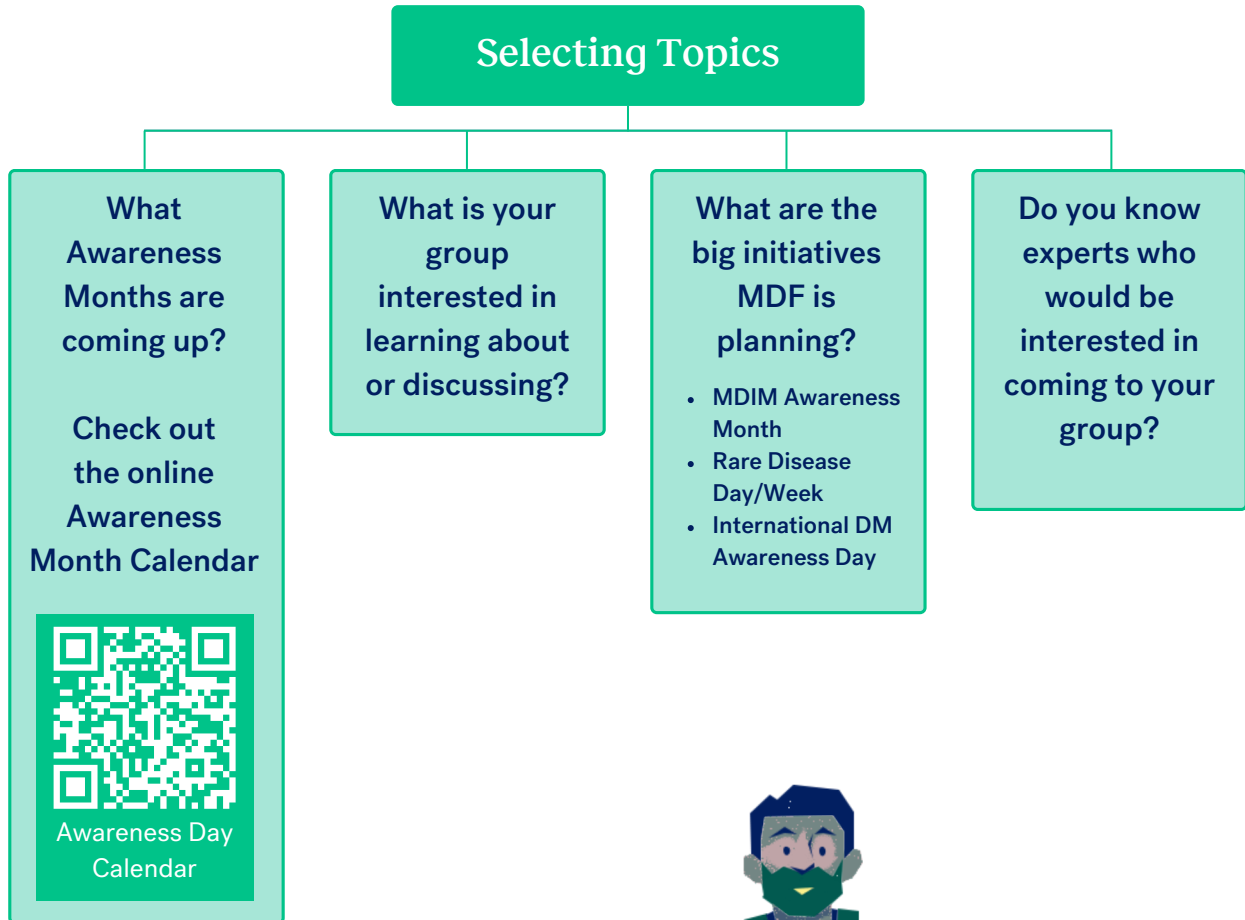
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MDF Support Group Meeting Ideas

✔ Leading a Group with Topics

We encourage SGFs to plan their group topics three months at a time. This allows you to be responsive to the needs and interests of your group.

Questions to Consider:



MDF Support Group Meeting Ideas

Meeting Topic Ideas and Associated Experts:

Nutrition & Diet Exercise Meditation

- Registered Dietician
- Physical and/or Occupational Therapists
- Certified Yoga Instructors
- Certified Mindfulness & Meditation Instructors

Research

- MDF's DM Family Registry Coordinator
- MDF Fellow
- Clinical Researcher
- MDF Chief Scientific Officer

DM Symptom Management

- Neurologist or physician specialty in DM
- Respiratory Therapists, Pulmonologists
- Ocular Specialists
- Executive Functioning Coaches
- Cardiologists or GI Specialists

Social Security and Disability Insurance

- Social Security Representatives
- Patient Advocate Foundation
- Licensed Social Workers

DM Questions, Info, and Resources

- Specialty physicians with expertise in DM
- Genetic Counselors
- MDF Staff

Reach out to MDF for Connections to Experts!

MDF Support Group Guidelines

Establishing Group Guidelines is an important facet of running a successful group. Guidelines can support the SGF's ability to maintain order and ensure everyone has an opportunity to speak.

This document has been designed for SGFs to use as a guideline for establishing group agreements with their participants. This document should not be shared outwardly.

Who May Attend an MDF Support Group

MDF Support Groups are open to community members who are affected with DM1 or DM2, and their caregivers. MDF Support Groups are not open to industry, researchers, clinicians, etc. If invited as speakers, they may only stay for their presentation and Q&A.

Confidentiality

One of the goals for a support group facilitator is to create a safe space for support group participants. There is an implicit trust established between the facilitator and support group participants. To honor this trust everyone is expected to treat each other with respect and not share any sensitive information that is shared; this includes sharing information verbally, or in written form. No notes about people's personal experiences may be written down and kept. Group meetings may not be recorded.

SGFs have an ethical obligation to maintain the integrity of the group's confidentiality. This includes not sharing information shared in your group with other SGFs.

Confidentiality should be held between participants as well. Participants should understand they are expected to be held to confidentiality agreements.

Self-Harm Scenarios

If a support group participant suggests that they may hurt themselves or someone else, please see the section: "Suicide Prevention" in your notebook. If you have questions about specific content a participant has shared, please contact MDF staff or the SGF Social Worker.

Medical & Mental Health Advice

SGFs do not serve in a clinical or healthcare capacity, regardless of their professional experience and/or licenses. Specific medical advice should not be shared. General information may be made available to the support group participants, but individual diagnosis and medical advice is to be avoided.

MDF Support Group Guidelines

✔ **Cross Talk**

The term “cross talk” refers to people interrupting someone while they are speaking. Especially during introductions or check-in you’ll want to maintain the focus on the individual speaking and not allow others to interrupt with comments or questions. A gentle, “let’s let [the person speaking] finish their check-in and we can ask them questions later,” often helps the situation. SGFs need to decide when interruptions and questions help keep the conversation going or if they are attempts to dominate or change the subject.

✔ **Mutual Respect**

At support groups, SGFs and participants will be likely to meet people very different from themselves, but with a common link of DM. SGFs and participants should keep in mind that all are part of the larger MDF family.

✔ **Everyone’s Experience is Valid**

Support groups are a safe environment for sharing experiences dealing with or supporting the DM community. They are a non-judgmental and open space; any negative remarks regarding religion, gender, sex, sexual orientation, disability, age or any other aspect of a person’s identify are not acceptable.

✔ **Speaking is Not Required**

If group participants do not feel like sharing, it is okay not to share. If others in the group choose not to share, we do not request they share.

✔ **Share the Discussion Time**

Everyone should have an opportunity to speak during the group.

✔ **Use Appropriate & Respectful Language**

SGFs and group participants should not use terms or swear words that are generally considered offensive.

✔ **No Clinical Trial Participation Discussions/Sharing**

SGFs and group participants should not discuss their or their loved one’s participation in clinical trials. Sharing what clinical trials exist is okay.

✔ **Use this Group for Its Intended Purpose**

SGFs and group participants do not advertise businesses, organizations unless it is MDF, or engage in self-promotion.

Tips for Facilitating Group Discussions (Living Proof Advocacy)

✓ To Encourage Participation

- Communicate your goals -- explain what you want to accomplish. People will be more willing to speak when they know what you're after.
- Appear open and interested:
 - Pause after you ask a question.
 - Be enthusiastic.
 - Maintain strong -- but not intimidating -- eye contact.
- Ask open-ended questions (who, what, when, why, where, and how).
- Ask follow-up questions.
- Listen and be patient.
- Focus on individuals; it's your job to make sure everyone participates.
- Don't communicate anticipated outcomes. You don't want listeners to think that you are after the "right" answer. Don't make it a guessing game or test.
- Let them say it; encourage your group to do the talking. Do what you can to make them feel good about what they have contributed.
- Maintain a safe environment (discourage harsh judgements and negative attitudes).

✓ To Control the Process

- Set limits. Let people know what you want to find out, why you need their participation, and approximately how long you'd like the discussion to last.
- Remind participants of what the goals and scope of the discussion are.
- Summarize and focus long, complicated responses.
- Make connections and plot trends.
- Ask yes or no questions when you want to slow the discussion and take control.
- Discourage excessive talkers by reminding them that you need to hear from everyone.
- Bring the discussion to a close at an appropriate time—when you have reached your goal or when it is no longer fruitful.
- Summarize the information the group has generated.
- Thank the group for their valuable input.



MDF Resources: Community

These publications are for a general audience to help understand the condition and various aspects of life with DM. You can access and share them all for free on the MDF website or the Sr. Manager of Community Engagement to get a hard copy mailed to you. (lucie.shiffman@myotonic.org)



An * indicates this resource is available in more than one language.

Medical Alert Card

Patients with myotonic dystrophy often exhibit adverse reactions to sedatives, anesthetics, and neuromuscular blocking agents. Ensure your emergency responders follow these critical guidelines.

My Clinic Visit Planner*

This planner enables families to discuss upcoming clinic visits and jot down important questions and information to help ensure it is covered at the appointment.

Going to School with Myotonic Dystrophy: A Guide to Understanding Special Education and IDEA

This comprehensive resource helps parents and family members take advantage of the Individuals with Disabilities Act (IDEA). The Guide covers services and mandates for ages newborn through 21.

Exercise Guide for Individuals with Myotonic Dystrophy*

This guide includes information on the benefits of exercise for DM, recommendations on aerobic activity, types of exercise, monitoring exercise, exercise strategies & finding motivation.

Health Insurance Considerations for People Living with Myotonic Dystrophy in the United States

MDF created this resource to help you navigate the process of making sure your medical treatments and medications are covered, and how to appeal your claim if it is denied.

Nutrition Guide for Individuals with Myotonic Dystrophy*

This guide is written and reviewed by nutritionists specialized in working with individuals with DM, and includes information on diet and DM, managing constipation, being overweight/underweight with DM, managing swallowing problems, feeding tubes, supplements, and sample meals.

Guide for Adults Affected by Juvenile-onset (JOA) Myotonic Dystrophy and their Caregivers

This Guide is specifically designed to help families affected by juvenile-onset DM understand how to manage their lives, especially at transition points in development and education.

Applying for Social Security Disability Benefits Toolkit

The toolkit is designed to assist those affected by myotonic dystrophy in navigating the application process for Social Security Disability Insurance (SSDI) benefits and Supplemental Security Income (SSI) benefits. (US Health System only)

Employment Access Toolkit*

MDF created this Toolkit to help individuals navigate the employment process and includes information on how DM can affect your job, how to assess your readiness to work, how to search & apply for a job, how to write a resume and cover letter, tips for interviewing and much more. (US Health System only)

Learn more at www.myotonic.org/toolkits-publications

MDF Resources: Healthcare Providers

These publications are for professional audiences – especially doctors and nurses – who treat and care for individuals living with DM. You can access and share them all for free on the MDF website or the Sr. Manager of Community Engagement to get a hard copy mailed to you. (lucie.shiffman@myotonic.org)



An * indicates this resource is available in more than one language.

Care Guidelines for Speech and Language Pathologists Treating Adults and Children with Myotonic Dystrophy

This guide is written and reviewed by an international group of speech and language pathologists who are specialized in working with adults and children with DM.

Clinical Care Recommendations*

Resources to improve and standardize care developed by more than 65 leading DM clinicians in Western Europe, the UK, Canada, and the US. Resources include recommendations for DM1 in adults and children, and adults with DM2.

Clinical Care Recommendations for Cardiologists & Pulmonologists Treating Adults with Myotonic Dystrophy Type 1*

Two separate resources for cardiologists and pulmonologists that provide care recommendations for treating adults with DM1.

Clinical Recommendations for People of Pregnancy Potential with Myotonic Dystrophy*

This resource is designed to provide clinicians with an overview of risks and care recommendations for individuals living with DM who are pregnant or considering pregnancy.

Occupational Therapy Suggestions for the Management of a Myotonic Dystrophy Patient

A quick reference excerpt for clinicians from the full MDF Toolkit.

Practical Suggestions for the Anesthetic Management of a Myotonic Dystrophy Patient*

Regardless of the form of DM or the severity of DM symptoms experienced, severe and life-threatening reactions to anesthesia are possible and should be monitored whenever anesthesia is administered.

Respiratory Care Recommendations for Myotonic Dystrophy Patients During the COVID-19 Pandemic*

This guide includes tips for patients, caregivers, & medical providers on the use of noninvasive positive pressure ventilation (NIPPV) if you have been exposed to or have symptoms of COVID-19 infection.

The Role of Physical Therapy in the Assessment and Management of Individuals with Myotonic Dystrophy

These Physical Therapy Guidelines for DM address the role that the physical therapist plays in DM care.

Learn more at www.myotonic.org/toolkits-publications

Outreach Templates

These templates offer a great way to reach out to new community members, touch base with community members you haven't seen in a while and find new ways to invite people to join MDF support groups.

Do not send out these templates without first ensuring the information about your group is added in the blanks and correct.

You may adjust these templates in the way that fit your voice best.

New Registration Outreach:

Use this template to reach out to someone new who has registered for your meetings, but has not yet attended.

Hello,

My name is _____ and I'm a Support Group Facilitator for Myotonic Dystrophy Foundation. I was excited to see you recently registered to attend our recurring Support Group, that happens every _____ at _____. These meetings provide an excellent opportunity to meet others managing DM and their loved ones and learn from one another

If you have any questions or would like to connect briefly before joining your first meeting, feel free to reply and we can find a time to talk.

I look forward to meeting you soon!

Warmly,
YOUR NAME

Outreach Templates

No Longer Engaged Outreach:

Use this template to reach out to someone who used to attend regularly but has been absent recently.

Hello,

I'm reaching out from the MDF _____ Support Group because I haven't seen you in a while! I know things often come up, and our schedules may change, but we would love to have you join us at our meetings again. If something has come up and these times no longer work for you, let me know and I can help connect you to another MDF Support Group that meets a different time. You can also review all MDF Support Groups on the MDF Event Calendar, here:

www.myotonic.org/calendar/month

If there are specific topics or discussions you are hoping to have in the group, let me know and we can plan for them in the future.

I look forward to seeing you soon!

Warmly,
YOUR NAME



Outreach Templates

Thanks for Joining Us:

Use this template to reach out to someone who joined for the first time to make them feel welcome and seen.

Hello,

It was so great to see you at our most recent MDF Support Group! I know attending your first meeting can be overwhelming, but we are so glad you joined us. Our next meeting is _____ and we would love to see you again Please let me know if you have any questions.

I look forward to seeing you again!

Warmly,
YOUR NAME



SGF Directory

Alexandra LeBoeuf -- Canada Virtual Support Group

alexl@sgf.myotonic.org

Ann Woodbury -- JOA Warriors & JOA Caregivers Support Group

annw@sgf.myotonic.org

Annette Rnjak -- Caregivers Virtual Support Group

annetter@sgf.myotonic.org

Araceli Mera -- International Spanish Speakers Support Group

aracelim@sgf.myotonic.org

Barbara Ochoa -- Southern California Regional Support Group

barbarao@sgf.myotonic.org

Bernhard Rogg -- International German Speakers Support Group

bernhardr@sgf.myotonic.org

Beth Feigenblatt -- Florida Regional Support Group

bethf@sgf.myotonic.org

**Bill Nuttall -- Adult Facebook Chat, DM1 Facebook Group, and
Massachusetts Regional Support Group**

billn@sgf.myotonic.org

Caroline Easterling -- Maryland Regional Support Group

carolinee@sgf.myotonic.org

Carolyn Valek -- Central Ohio Regional Support Group, JOA Warriors Support Group

carolynv@sgf.myotonic.org

Chuck Hunt -- Atlanta Regional Support Group

chuckh@sgf.myotonic.org

Cindy Hubert -- Washington State Regional Support Group

cindyh@sgf.myotonic.org

David Kugler -- International Spanish Speakers Support Group

davidk@sgf.myotonic.org



SGF Directory

Emily Jones -- Fingerlakes Regional Support Group

emilyj@sgf.myotonic.org

Erin Beucler -- DM1 Facebook Group

erinb@sgf.myotonic.org

Glenda Wilson -- New York City/New Jersey Regional Support Group

glendaw@sgf.myotonic.org

Guillermo Zubillaga -- New York City/New Jersey Regional Support Group

guillermoz@sgf.myotonic.org

Haley Martinelli -- DM2 Virtual Support Group #2, MDF Board Member

haley@sgf.myotonic.org

Jan Jaffe -- New York City/New Jersey Regional Support Group

janj@sgf.myotonic.org

Jeannine DeSoi -- Massachusetts Regional Support Group

jeannined@sgf.myotonic.org

Jim Dolan -- Affected Men's Support Group

jimd@sgf.myotonic.org

Jodie Howell -- Virginia Regional Support Group

jodieh@sgf.myotonic.org

John Cooley -- Kansas City Regional Support Group

johnc@sgf.myotonic.org

Jonathan Freedman -- Washington State Regional Support Group

Jonathanf@sgf.myotonic.org

Julie LeBoeuf -- Canada Virtual Support Group

juliel@sgf.myotonic.org

Kathie Thorsland -- Mountain West Regional Support Group

kathiet@sgf.myotonic.org



SGF Directory

Kim McPeek -- DM2 Caregivers Support Group

kimm@sgf.myotonic.org

Kim Reynolds -- DM2 Caregivers Facebook Group

kimr@sgf.myotonic.org

Kristen McClintock -- Florida Regional Support Group, DM Virtual Happy Hour

kristenm@sgf.myotonic.org

Lois Schenk -- Fingerlakes Regional Support Group

loiss@sgf.myotonic.org

Mark Coplin -- Portland Oregon Regional Support Group

markc@sgf.myotonic.org

Mindy Kim -- Carolinas Regional Support Group, Adult Facebook Chat, and DM Virtual Happy Hour

mindyk@sgf.myotonic.org

Nathan Beucler -- DM1 Caregivers Facebook Group, Central Ohio Regional Support Group

nathanb@sgf.myotonic.org

Patricia Gibson -- Kansas City Regional Support Group

patg@sgf.myotonic.org

Rashid Kassir -- San Diego Regional Support Group

rashidk@sgf.myotonic.org

Rob Besecker -- Chicago Regional Support Group

robb@sgf.myotonic.org

Rose Albanese -- Southern California Regional Support Group

rosea@sgf.myotonic.org

Ryan Vogels -- Chicago Regional Support Group, Affected Men's Support Group

ryanv@sgf.myotonic.org



SGF Directory

Samantha Welsh -- Virginia Regional Support Group, Caregivers Facebook Group
samanthaw@sgf.myotonic.org

Sarah Berman -- Caregivers for Children Living with Congenital Myotonic Dystrophy Support Group
sarahb@sgf.myotonic.org

Scott Virgo -- Michigan Regional Support Group
scottv@sgf.myotonic.org

Shaun Moore -- Affected Men's Support Group
shaunm@sgf.myotonic.org

Suzanne Perkins -- Michigan Regional Support Group
suzannep@sgf.myotonic.org

Ted Salwin -- Caregivers Virtual Support Group
teds@sgf.myotonic.org

Tom McPeck -- DM2 Virtual Support Group, DM2 Facebook Group, MDF Board Member
tomm@sgf.myotonic.org

SGF Agreement

Support Group Facilitators (SGFs) for the Myotonic Dystrophy Foundation (MDF) are essential for achieving the MDF mission: Community, Care and a Cure.

- We support and connect the myotonic dystrophy community.
 - We provide resources and advocate for care
 - We accelerate research toward treatments and a cure.
-

The SGF team plays a vital leadership role within the DM community. SGFs are volunteer community leaders who receive training and support from the MDF to create spaces for those living with DM, and their caregivers to confidentially share their experiences, learn from others impacted by DM, and access resources and information to help improve quality of life.

SGFs provide leadership for support groups that are sponsored by the MDF. SGFs make a two-year commitment and agree to follow the SGF roles, responsibilities, and support group policies provided by the MDF. All SGFs must host a minimum of four support groups per year to remain in the position.

Support Group Management:

- SGFs should have access to adequate technology necessary to perform their volunteer work.
- Collaborates with support group co-facilitator (if you have one).
- Coordinates support group meeting logistics either in-person or virtually, including frequency of meetings and meeting date.
 - For in-person: identifies appropriate location, secures meeting fees, and procures snacks and/or refreshments.
 - For virtual meeting: works with MDF to establish Zoom.
- Ensures MDF has correct meeting dates and times set up for promotion and events calendar.
- Communicates meeting date and time to group participants either via phone or email.
- Attends and leads support group meetings as scheduled.
- If meeting guests are desired, generates topic ideas for support group meetings and recruits, or works with MDF to recruit guest speakers.
- Raise awareness of current MDF educational initiatives, including resources available at www.myotonic.org, special events, and conferences.

SGF Agreement

Communication with MDF:

- Attend quarterly one-on-one meetings with the Sr. Manager of Community Engagement.
- Provide MDF with up to date meeting information such as date and time at minimum once every six months.
- Communicate special speaker or topics 3 weeks in advance of meeting date.
- Communicate special and/or difficult situations or incidents which arise during a support group meeting within 48 hours.
- Document support group meeting via the SGF meeting form (if your group does not have Zoom registration).
- Should an SGF plan to host a group in a private home or business, he/she/they must first seek MDF's approval, as well as provide documentation of insurance.
- Speakers secured by SGFs should be shared with MDF prior to confirming their speaking engagement for the group.

Participation in Training:

- Attend monthly SGF virtual meeting, at least quarterly
- Attend, either in-person or virtually, Annual SGF training

Leave:

It is recognized that SGF's may need to step away from their role due to personal situations, either temporarily or permanently. In this case, SGF's should contact the Senior Manager of Community Engagement as soon as this need arises so that a smooth transition may occur for both the SGF and their support group participants.

Confidentiality:

As an MDF Support Group Facilitator activities may be performed which may require disclosure of confidential or proprietary information (confidential information is any information of any kind, nature, or description concerning any matters affecting or relating to the services for Foundation, business or operations, donors, data, researchers, clinicians, and/or those served by Foundation.)

SGF Agreement

- SGF will hold the confidential information received from MDF or anyone it serves in strict confidence and shall exercise a reasonable degree of care to prevent disclosure to others.
- SGFs will not disclose or divulge either directly or indirectly the confidential information to others unless authorized to do so in writing by MDF.
- SGFs will not reproduce confidential or proprietary information, resources or tools, nor use this information commercially for any other purpose other than the performance of his/her/their duties for MDF.
- SGF will, upon the request, or upon exit or termination, deliver to MDF any notes, documents, and materials received from MDF or originating from their activities for MDF.
- The obligation to protect information confidentiality will survive SGF's term in their role, and will last indefinitely unless otherwise stated.

Signature:

MDF reserves the right to take disciplinary action, up to and including termination from the volunteer SGF role for violations of this agreement.

I agree to be held to the above SGF Agreement requirements.

Signature

Date

Printed Name



www.myotonic.org