



MDS SUPPORT GROUP LEADER'S TOOLKIT

A Helpful Guide for Support Group Leaders



www.mds-foundation.org

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THE MYELODYSPLASTIC SYNDROMES (MDS) FOUNDATION, INC.

VISION STATEMENT

Support everyone affected by Myelodysplastic Syndromes (MDS) while advancing the search for a cure.

MISSION STATEMENT

The MDS Foundation, Inc. is an international non-profit advocacy organization whose mission is to support and educate patients and healthcare providers with innovative research into the fields of MDS, Acute Myeloid Leukemia (AML) and related myeloid neoplasms in order to accelerate progress leading to the diagnosis, control and cure of these diseases.

MDS SUPPORT GROUP LEADER JOB DESCRIPTION

Be available for contact from other myelodysplastic syndromes patient(s) and/or caregiver(s).

Your contact information (phone and email address) will be listed on the MDS Foundation website. The Facilitator of Support Group meetings is responsible for the operation of the meetings. The support group facilitator is there to guide the group, stimulate discussion, manage the group dynamics, and encourage interaction.

RESPONSIBILITIES:

- Arranges meeting place.
- Identifies topics for meetings.
- Coordinates speakers as required.
- Introduces and thanks speakers at meetings.
- Provides for refreshments.
- Ensures security of location.
- Provides information to the MDS Foundation for newsworthy items, as required.



(Note: MDSF will provide start-up funds to offset the costs of the initial meeting.)

SUGGESTION FOR TIME REQUIRED:

- One meeting per month (approx. two hours/month)
- Speaker coordination (approx. two hours/month)

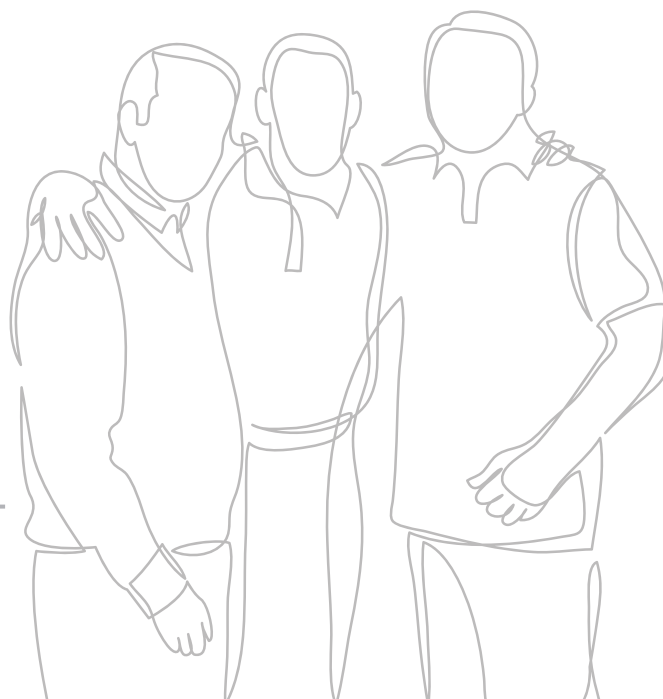
REMEMBER

The Support Group is there to support those living with MDS and their families. Don't be afraid to survey them to find out what they would like to discuss or learn during a meeting.

It is worth noting that not all of the following topics will be appropriate for all participants. For instance, talking about death and dying may upset newly diagnosed individuals.

Plan and facilitate Support Group meetings

Frequency of meetings may depend on interest level, travel requirements and weather conditions. Meetings should be in locations that do not charge a fee, such as cancer centers, hospitals, churches, libraries, community centers or members' homes. To stimulate interest among members, we recommend that you offer a range of program formats. Suggestions include guest speakers, educational sessions via internet or DVD, themed discussions or general Group sharing, or discuss research updates (invite a hematologist, researcher or drug company representative). (Note: Caution, the speakers should not recommend a certain therapy or drug to individual/s.) Every meeting should include an opportunity for members to share experiences, questions and concerns even if it is for a limited time following a presentation by guest speaker. At all meetings, new members should be introduced and offered the chance to share their personal story, if desired.



Communicate your meetings

The MDS Foundation (MDSF) website www.mds-foundation.org is accessed worldwide. Inform the MDSF Office (ahassan@mdsf-foundation.org) as soon as your meeting is confirmed so that meeting information can be added to the calendar of events on the MDSF website. A Support Group Meeting Attendance form is included in this guide. Circulate this form at meetings to obtain member information with total attendance. **US Support Groups are encouraged** to send a list of their meeting attendees to the MDSF Office so that they will be added to the MDSF database and receive timely information about events, MDS and MDSF resources. Recognize the importance of keeping your list of MDS patients and caregivers current...and inviting them to your Support Group meetings. If you are aware of new members, loss of members or changes in contact information, please advise the Office.

Communicate with your Support Group members

Send Support Group meeting notices several weeks in advance so that members can plan ahead. Reminders can be sent closer to the meeting date. You may share news of interest to your Group, such as a local cancer-related meeting or a link to a key MDS presentation. When emailing to your Group, use the **Bcc** option to protect the privacy of your members' email addresses. REMINDER: Make sure that your meetings/events have been sent to the MDSF Office prior to sending meeting notices to your members so that they can refer to the MDSF website if they would like.

STAY INFORMED ABOUT NEW MDS-RELATED DEVELOPMENTS AND PATIENT ISSUES

If possible, consider joining the MDSF internet-based message board forum to participate and connect with others in discussions on all aspects of MDS and sharing of concerns and positive experiences. You can find our MDSF Patient Message Board here <https://www.mds-foundation.org/forums/forum/patient-message-board/>.

If you are able, plan to attend our MDSF Patient & Caregiver Forums. We hold ten in the US and at least one outside of the US annually. These events can be found at <https://www.mds-foundation.org/patient-and-family-forums/#upcoming-patient-forums>.

The educational forums are a wonderful opportunity to learn about the latest MDS developments from hematologist-oncologists who are experts on MDS along with others who have MDS.

Assistance from the MDS Foundation

To help you succeed, the MDS Foundation aids in many ways:

- **Support Group Leader's Toolkit for US Support Groups** – a comprehensive manual with a detailed description of the process of Support Group development, including list management, program planning and Group facilitation.
- **MDS Foundation website** www.mds-foundation.org – includes helpful information regarding the organization, services, medical topics, videos and presentations on MDS.
- **Online Group Message Board** – a service where MDS-related topics are discussed by patients and caregivers – <https://www.mds-foundation.org/forums/forum/patient-message-board/>.
- **MDS Foundation Centers of Excellence** at <https://www.mds-foundation.org/mds-centers-of-excellence-map-new/> – a list of MDS experts (US and International) for second opinions.
- **MDS Foundation Newsletter** – publication that features articles on the latest MDS research and treatments, MDSF US and International activities and personal stories of MDS patients and their caregivers.
- **MDS Foundation Social Media** – Support Group notices distributed via MDSF-specific Facebook and Twitter accounts.
- **Contact: Audrey Hassan, Patient Liaison, MDS Foundation, Inc. (ahassan@mds-foundation.org)**.
- **MDS Foundation Office** – Tel: 1-800-637-0839 for general information and to order resources to distribute for your group.
- **Other Support Group Leaders** with similar Groups who are willing to help you – list and contact information can be found on the MDSF website <https://www.mds-foundation.org/global-patient-support-groups/#US-MDS-Support-Groups>.

***THANK YOU for even thinking of doing such
an important job for the MDS community.
We truly appreciate your interest.***



MDS SUPPORT GROUPS

MAKING A DIFFERENCE ONE PERSON AT A TIME

The very best part of the MDS Foundation is our members and the support we share. Although we gather for our MDS Patient & Caregiver Forums, local Support Groups provide a more frequent opportunity for members to meet, share information and experience and provide mutual encouragement.

Many patients consider Support Groups a meaningful component of their care in living with myelodysplastic syndromes. They come to Support Group meetings to learn more about their disease and gain social support. MDS support groups focus on education and support. Promotion of empowerment (active involvement in health-related decision-making), positive emotional adjustment to MDS and a sense of community are primary goals of the Support Group experience. Myelodysplastic syndromes are considered a rare cancer; therefore, it is highly recommended that patients educate themselves so that they are able to share and discuss the latest treatment options with their hematologists in a partnership relationship. A well-educated patient receives the best care! Many patients feel a bond of friendship with other Support Group members who have MDS, and a sense of community develops. Most importantly, local Support Group meetings offer an opportunity for sharing MDS-related experiences, asking questions and receiving feedback from members, a benefit that is hard to find in other venues. For most members, this period of sharing is the heart and soul of the Support Group experience.

MDS Support Group practices vary from location to location and are decided upon by the needs of the members themselves. Some Support Groups meet in members' homes, others meet in community meeting facilities or hospital conference rooms. In order to accommodate the needs of Support Group members, meetings may be held on weekends or weekdays, daytime or evening. A Support Group meeting agenda may include presentations on the latest MDS research and treatment, survivorship issues in living with MDS, updates on MDSF activities or local fundraising efforts and an opportunity for Group sharing among members.

THE MDS FOUNDATION, SUPPORT GROUP LEADERS AND SUPPORT GROUP MEMBERS WORKING TOGETHER

The MDS Foundation, Support Group Leaders and members work together to provide the best possible experience in meeting the Support Group goals.

Support Group Leaders – The MDSF welcomes you to a wonderful team of people who have agreed to lead a Support Group for patients diagnosed with myelodysplastic syndromes, their families and friends. We are delighted that you have decided to become a Support Group Leader and hope that you find the experience very rewarding.

MDSF – The MDSF provides many sources of assistance to the Support Groups as noted in the Support Group Leader Job Description section of this Guide.

Support Group Members – In addition to the MDSF and Support Group Leaders, Group members have a responsibility to contribute to a positive Group experience. At each individual's comfort level, members share personal MDS-related experiences with others in the Support Group. It is recommended that members make an effort to come to meetings on time and not attend if they are ill with an infectious condition. Response to others in the Support Group should be made in a respectful and non-judgmental manner. Information shared by members in the Group is confidential and not shared outside the Group.



STARTING A SUPPORT GROUP

If you are interested in starting a Support Group, the first step is to contact the MDSF Office – Audrey Hassan, ahassan@mds-foundation.org or phone: 1-609-298-1600 Ext. 210. After discussing the role, the need in your area and deciding that you do want to become the local Leader, we can help you get started. The MDSF can help by sending your support group meeting schedule to those in our member database who live in your target area of approximately 1-2 hours driving distance from your meeting location. In sparsely populated areas, a target area may be larger. The area may include one or more states or partial areas within states.

MEMBERS LIST MANAGEMENT

You will need a system for organizing and managing your list of members that includes names, home and email addresses, and phone numbers. This task involves some computer skill.

Changes may occur with your Group due to death or relocation of a member. If you hear of the death of a member, please ask the person who notified you if you can share the information with the members of your Support Group who had a personal connection with the member, including home and/or email addresses for condolences. If a member moves, please ask him/her if you can inform the Support Group and share the new home and/or email address. In both situations, if there is agreement to share the news, send a note to the list (**Bcc**) with details and copy (**Bcc**) the person who shared the information. Please inform the MDSF Office as soon as possible of any changes to a Group member's contact or status information so that the Office records can be updated as well.

COMMUNICATION: MDS PATIENT SUPPORT GROUP MEMBERS/MEETINGS/EVENTS

An important Leader function is the **communication with newly diagnosed MDS patients**. Newly diagnosed patients who are often fearful and confused may call for information, encouragement and support. As the point of initial contact, a Leader is in the ideal position to help the MDS patient begin a journey that will lead to the best possible MDS experience. Leaders assist the MDS patient in finding sources of education and support, such as: 1) **MDSF website** – medical information, publications, stories of hope, services (Support Groups and meetings) and list of physicians for second opinions (MDS Centers of Excellence); 2) **Info Packet** of information for the newly diagnosed available by contacting the MDSF office; 3) **MDS Online Message Board**; 4) if interested, an **"MDS buddy"** to connect with who may have similar issues; and 5) invitation to your next **Support Group meeting**. Actively listen to the patient, addressing his or her needs in an empathetic

and encouraging manner. Respond non-judgmentally, offer suggestions when appropriate, but do not give medical advice. Let the patient know that the MDSF and you are **here to help**. A sample new member letter, “Welcome to our MDSF Support Group” is included in the Appendices, page 23 as a guide for communicating important MDSF services to new members via email.

Leaders generally communicate with the people on their list by email. If a person is listed without an email address, please ask them to share one with you, possibly a child or other relative. If that is not an option, the member can be notified of meetings by mail or phone call. Occasionally a yearly meeting schedule is sent and a reminder before each meeting. For planning purposes regarding space and refreshments, you may want to request RSVPs from members who plan to attend.

Leaders use various methods for sending emails to their Support Groups. Some email directly from the member list on an Excel spreadsheet that is updated by you. Other Leaders may prefer to set up a contact group in their email account. All email communication with your Support Group should be sent using the **Bcc** feature of your email system so that every member does **NOT** receive all other members’ email addresses. This maintains **privacy** and **confidentiality**.

The MDSF website is accessed worldwide. Please use it to communicate your meetings by having your meeting posted on the MDSF calendar. As soon as your meeting is confirmed, please notify the MDSF Office – Audrey Hassan, ahassan@mds-foundation.org – with the following meeting information: name of Support Group meeting; date/time; location (facility, number and street, city, state/province/country and zip or postal code...your contact information (name, phone and email); and name of speaker if desired.

In addition to posting on the MDSF website, announcements can be communicated via social media channels or sent to the local newspapers or cancer centers. Consider contacting other advocacy organizations as well, like The Leukemia & Lymphoma Society (LLS) and/or additional blood cancer organizations for inclusion in their newsletters. Design a flyer announcing the meeting and distribute or post at local hospitals or hematology-oncology offices. A sample flyer is included in this handbook. Many hematology offices have bulletin boards and will let you post announcements with the pull-off contact tabs on the bottom. To promote interest among local oncologists, it may be helpful to focus communication about MDSF services with the nurse practitioner or patient navigator and send the meeting notice with program flyer attached to the hematologist and nurse. A sample letter to Health Care Professionals is included in the Appendices, page 26, as a guide to use for promoting referrals to the local Support Group.

Joint meetings can also occur with LLS and country-specific blood cancer organizations, where these groups invite their members and you invite your Support Group members. Organizations like the LLS may also assist in providing rooms, refreshments or expert speakers. If interested, contact your local LLS Chapter at www.lls.org to determine collaboration possibilities in your area.

MEETING LOGISTICS

When to Meet

Meeting times are agreed upon by general Support Group consensus. Most Support Groups find that Saturday or Sunday works best, and they typically meet for two or three hours between 11:00 am and 4:00 pm. Alternatively, your Support Group may find it convenient to meet in the evening, during the week or for an extended period of four hours that involves a meal break during the meeting or afterward.

Support Group meetings are ideally held three or more times per year and at a minimum, twice per year. Factors relating to how often the Support Group meets include travel distances, preference of Group members and climate. If attendance at meetings decreases, perhaps you should poll your Support Group to determine if members generally want to meet less often or if there is another unmet need, such as program content. Consider holding educational meetings annually to provide updates and education to members.

Where to Meet

MDS Support Groups gather in meeting rooms at various facilities including hospitals, churches, libraries, country clubs, retirement villages, local cancer centers, colleges/universities, other blood cancer organizations and the US Cancer Support Communities. Members' homes provide an intimate setting for smaller Groups. Personal oncologists may be helpful in securing rooms at cancer centers. **Don't be afraid to ask.** In evaluating local facilities, consider the following criteria: 1) cost – ideally, the facility should be free; 2) convenient parking; 3) comfortable seating to accommodate the size of the Group – a very large room for a small Group will not promote intimacy; 4) convenient restrooms; 5) accessibility for disabled persons; 6) access to audiovisual equipment – DVD player, TV, projector, screen, computer and microphone hookups; and 7) kitchen facilities as a bonus for refreshments.

The location of the meeting facility should be as convenient to as many people as possible. Some Groups alternate meeting locations to accommodate more members in their target area.

For large Groups, it may be helpful to have stick-on name tags, next to the Meeting Attendance form, for name recognition. Some Groups color code name tags or markers, one for MDS patients and one for all other guests. Thick markers promote easy name recognition.

Other tables will be needed for MDS and health-related literature and refreshments.

A friendly volunteer from your Group can act as a greeter to warmly welcome people as they arrive. This person will direct people to the sign-in and literature tables and introduce them to others.

Room setup with chairs in a circle seems to encourage warm, cozy interaction. If possible, avoid sitting around tables as they become barriers. It is better to have a smaller circle, 10-14 feet, and set up a second or third row behind, than one large circle. Chairs set up in rows may be preferable for a larger meeting with a speaker presenting from podium or for viewing a recorded presentation.

Refreshments

If you prefer, stick to the basics regarding refreshments, such as coffee, tea, juice, sparkling water, crackers, cookies and cut up veggies and fruit. Some Groups ask for volunteers to take turns bringing refreshments. You might want to focus on a wellness theme and ask members to bring healthy snacks, such as hummus, nuts, berries and whole grain crackers. Potlucks are an opportunity for all to contribute and share a favorite dish. Mixing it up with a variety of ideas adds interest.

MEETING AGENDA

Meeting agendas vary considerably based on the program structure and size and needs of the Support Group. Try to start and end on time to respect the schedules of all attendees. If you are reserving a room, make sure you allow time for set up and for impromptu discussions that will precede and follow the formal meeting.

It is recommended to begin the meeting with an introduction of yourself and a review of the agenda. At this time, you can announce the date of the next meeting, review MDS news and events and ask for members' ideas about future meeting topics and speakers. It is important to communicate that their input about Support Group functions is valued.

A typical meeting agenda may include several components: 1) education in the form of a key topic presented by a speaker or an online/DVD video; 2) group sharing; and 3) social mingling/refreshments. If a speaker is presenting, group sharing can be abbreviated, but new members should always be given the opportunity to share.

Each member who is comfortable sharing his/her MDS experience will provide information that may include:

1. Name and town/area of residence
2. Year of diagnosis
3. Treatment experience(s)
4. Health status and quality of life
5. Expectations from Support Group



Emphasize sharing a **brief** discussion of their MDS story so that everyone has a chance to talk. After everyone has shared their story, an issue that has been raised can be addressed in more detail. Most people want to talk about their experience with myelodysplastic syndromes and are often debating about a treatment decision or are worried about a symptom. Hearing the experiences of others can offer guidance and support.

One of the most difficult situations for the Leader to manage is when one or two people in the Group want to spend an inordinate amount of time talking about grandchildren, politics or hobbies while others are frustrated, being too polite to interrupt. To deal with the situation, the Leader might comment: "Yes, outside interests are very important so that we can balance MDS within our lives. Perhaps we should get back to that point about..."

Another option is to introduce a new person and give that person more time to share. This often generates discussion about that person's particular situation and similar shared experiences by others in the Support Group. If you choose that approach, it is recommended that you speak with the person in advance. Some newer members may want a chance to "get to know" the Support Group before they are comfortable speaking.

If someone in the Support Group hasn't spoken, the Leader should check in with him/her specifically. A recommended approach is to address the person and ask, "How are you doing?"

Providing a short **medical update** at your meetings of new advances in MDS research and treatment is a great way to help members remain current. Support Group meetings provide a convenient small Group setting where members can learn about key developments relevant to treatment decision-making in discussions with personal oncologists. If you are not comfortable with this process, maybe a knowledgeable member in your Support Group would like to become involved in this manner.

Process:

- As a suggestion, the Support Group Leader, a knowledgeable designated member or a speaker via conference call (possibly an MDS healthcare professional) can provide a 10-15 minute update at Support Group meetings as new developments occur.
- Sources of reliable up-to-date information can be found at the following locations:
 - *The MDS News* printed newsletter
 - Information shared via our monthly e-newsletter, *The MDS Minute*
 - Current Myelodysplastic Syndromes clinical trials now enrolling on www.mds-foundation.org and www.clinicaltrials.gov.
 - The MDS Foundation website at www.mds-foundation.org for recent news updates
- If questions arise that you are unsure about how to address, please refer members to the information sources mentioned or to their oncologist. It is better to say “I’m not qualified to answer your question” than to give incorrect information.
- Most Support Groups have a time during the meeting for people to mingle, either at the beginning or the end of a meeting, to promote socialization and a sense of community. This informal period also offers members a chance to speak further with others on an individual basis about specific issues. If you’re reserving a room for a limited block of time, you should have a buffer before and after the meeting to accommodate these discussions.
- In order to continue to provide a meaningful Support Group experience for your members, it is helpful to provide the opportunity for members to evaluate their experience on a personal level. This can be achieved through an evaluation survey on an annual basis at a Support Group meeting and/or email. A sample evaluation survey is included, Appendices, page 22.

CAREGIVER BREAK-OUT SESSIONS

Some Support Groups have break-out sessions for caregivers separate from the patients. This works best for larger Support Groups. An important guideline is that caregivers should speak in first person about their own feelings, concerns, questions, attitudes and coping abilities, instead of talking about the patients’ particular situations. A recommended Group size is four to five caregivers. The facilitator of the Group should emphasize that privacy is an important ground rule so that caregivers can speak openly about an issue with a patient.

BUILDING AN EFFECTIVE SUPPORT GROUP

Facilitator Tasks:

1. Creation and maintenance of the Group – effective early effort in Group creation will lead to a well-functioning Group.
2. Build a Group culture – identifying acceptable topics and behavior.
3. Ongoing direction and Group guidance.

Establishment of Group Norms:

Norms are spoken and unspoken rules of expectation in the Group. Explicit norms reflect outspoken messages, such as confidentiality and avoiding the Group due to illness (cough, cold). Implicit norms relate to implied messages, expectation regarding going off topic, expression of emotion, Group tasks (what the Group wants). The facilitator shapes norms through verbal expression, non-verbal cues (nodding, ignoring) and personal role modeling behavior.

Challenging Group Members:

Monopolist – most common and most disliked member who talks frequently about related and unrelated events with excessive details. Possible factors relating to this behavior include anxiety, need to conceal personal information, fear of control and need for attention. This behavior has a negative effect on the Group which may lead to reduced attendance and members dropping out of the Group. Facilitator tasks may involve mentioning a time limit up front or not encouraging the behavior with non-verbal cues, such as nodding; however, in the interest of others in the Group, interrupting in a kind way may be necessary. Perhaps using the phrase “it looks like you are wandering” or something similar.

Silent Member – communicates very little in Group. Motives contributing to this behavior may reflect fear of expressing anger or of saying something that will be judged negatively. Additionally, the member may be new in Group and typically quiet in Group settings. The facilitator can comment on their non-verbal behavior and encourage them to share by asking open-ended questions.

Boring Member – is inhibited, lacks spontaneity, and the quality of shared experiences is poor. These members tend to have flat affect. The facilitator can address this situation by encouraging the member to stay on topic and share relevant information.

Help-Rejecting Complainer – listens to advice but does not accept it and repeats his/her complaints. The facilitator should not invest too much time in sympathetic feedback, but instead reflect on the content of the member’s negative feelings.

PROGRAM IDEAS/TOPICS

Meeting Topics for Speaker and/or Support Group Discussion – shared by our Leaders that may be addressed by expert professionals, patients or caregivers through in-person or video presentations:

MDS disease – pathophysiology, genetics, meaning of blood and laboratory test results and treatment options, including treatment relapse management; topic presented by hematologist who is knowledgeable about MDS.

Emotional factors – feelings related to loss (anger, sadness, despair); techniques for effective coping (support, meditation, counseling); achieving a “new normal” way of life; topic presented by clinical psychologist or social worker

Lifestyle factors – nutritional guidelines for MDS and overall well-being, physical activity options and benefits (including yoga and tai chi), managing personal stress situations presented by health care professional in this field.

Spirituality connection – finding a source of spirituality that is personally meaningful.

Partnering with healthcare professionals – asking key questions and shared treatment decision-making as an empowered patient.

Clinical trials – overview of all active clinical trials noted on www.clinicaltrials.gov, discussion of the clinical trial process, common considerations and benefits in entering a trial.

New drug update – review of new targeted MDS therapies by a pharmacist who specializes in oncology.

Research update – review of current research projects by knowledgeable MDS patients or healthcare professionals.

Basic MDS-related immunology and genetics – presented by scientists or physician specialists.

Managing side effects of treatment (short- and long-term) – presented by nurse practitioner or palliative medicine physician.

Common MDS issues – transfusion dependency and fatigue – topic presented by healthcare professional with expertise in these areas.

Acupuncture – management of symptoms (pain, fatigue, stress and nausea) presented by professional acupuncturist.

Legal and insurance issues – wills (including living will), power of attorney, bequests and health and disability insurance.

Financial support – led by financial cancer resource expert.

Medical ethics – led by professional medical ethicist.

Quality of Life Concerns – palliative care presented by palliative medicine health care professional.

Caregivers or care partners – essential aspects of the role these support people provide to MDS patients.

Patient-Caregiver communication – discussion of what patients want caregivers/care partners to know and what caregivers/care partners want patients to know (ideally in separate groups).

MDS Foundation website searching – demonstration of searching for key information on the MDSF website.

Focused Group sharing – members sharing ideas and experiences regarding a specific topic, such as living well with MDS (achieving a “new normal” life), coping with relapse, making treatment decisions in balance with life goals, etc.

Patient panel – members are selected based on common issues or experience. For example, a panel of clinical trial participants could share reasons for choosing the trial, obligations, medical care, expense, results, side effects, etc. A common treatment (transfusions) or MDS-related issue (fatigue) could be effectively addressed in a patient panel.

Joint meeting – if possible, a combined meeting with The Leukemia & Lymphoma Society (LLS) or local cancer center is an opportunity to share resources and widen the audience for a general cancer topic. These organizations may also be able to assist with securing meeting rooms, refreshments, speakers and publicity in their newsletters.

Tour of infusion room – the local cancer center may be willing to provide a tour of its facility.

Social events – picnics, potlucks or restaurant meals promote socialization and support.

The following discussion of key considerations when a **guest speaker** will be presenting at your meeting may be helpful. Plan at least a couple of months in advance to allow for speaker preparation time and coordination of schedules. Communicate with speaker regarding the major content areas of the presentation to meet Group needs/interest. Prior to the event (1-2 weeks), provide an estimate of participation level, reconfirmation of meeting location and time/date, plus your contact phone number. Some speakers are willing to take questions from participants ahead of the meeting in order to personalize their presentation for improved interest. The MDSF does not provide honorariums for speakers. Of course, a thank you note is always sent to speakers either via email or regular mail.

Sharing Your Support Group's Meeting/Event Highlights

It is helpful to share a brief meeting recap with your member list shortly after the meeting to update those who could not attend and to provide follow-up information, such as links/resources on related meeting topics and upcoming events. In addition to the informational value, this important communication will promote interest and a sense of community.

We encourage each of our Support Group Leaders to forward an update of their Support Group's activities/last meeting for publication in a future MDS News newsletter. We would also like to have 1–2 photos of a few members in your Support Group, if possible. Make it known that the photo(s) may be published in the MDS News so that members have the opportunity to decline being photographed. In addition, if names of members are included in Support Group summaries, please make sure the member(s) give approval to have their name(s) published in the newsletter. If you prefer, a volunteer from your Support Group with an interest in writing can assume the responsibility for writing meeting summaries.

AWARENESS TO LOCAL HEMATOLOGIST-ONCOLOGISTS

It is critical that local doctors and cancer centers are given as much information as possible so that they can provide resources for their patients. You can join us in raising awareness of MDS by distributing the MDS Foundation Brochure. Send a request to patientliaison@mds-foundation.org and let us know how many brochures you can distribute and your postal address. We will send them to you.

Encourage your members to please ask their doctors to inform any other MDS patients they have in their practice about your Support Group.

The MDS Foundation maintains a list of MDS Center of Excellence experts. These experts in the field of MDS provide consultations to patients and other physicians. This list of MDS clinicians can be found at <https://www.mds-foundation.org/mds-centers-of-excellence>.



PROVIDING SUPPORT: DEATH OF A SUPPORT GROUP MEMBER

The unfortunate event of the death of a Support Group member requires sensitivity and compassion in support of family members and throughout the Group experience surrounding this event.

If you hear of the death of a member, please inform the MDSF Office as soon as possible so that their records can be updated. The Office sends a letter of condolence to the family/friend of the member who has died. Leaders may communicate this news via email to members (**Bcc**) who knew the member personally, with permission of the person who shared the news, and copied (**Bcc**) on the email. Leaders who have had personal contact with the member and/or family may want to send a personal note of condolence. A warm invitation to the family member/friend to stay involved with the Group may help in the grieving process.

In situations where the deceased member was personally known in the Support Group, it is helpful for the Leader to facilitate the process of sharing the loss with the Group at a Support Group meeting. This sharing experience may include remembrances of the person and a discussion of members' thoughts and feelings of the impact of the loss on a personal level.

FINANCIAL SUPPORT

It is recommended that our patient support groups be as self-supporting as possible; however, we understand that expenses do occur in offering quality meetings. Many Support Groups are able to locate a free meeting room – options are noted in the “where to meet” section. Most Groups have little postage expense with the use of email. Responsibility for refreshments can be rotated among members or shared with potlucks. Some Leaders cover refreshment expenses personally. Speakers generally do not charge anything for their services. Certain Groups will give the speaker a small gift or make a donation to the MDS foundation in the speaker's honor. The MDS Foundation does not pay honorariums for speakers. Please clarify the speaker's requirements for honorariums in the initial discussion so that there is no misunderstanding later. A thank you note to your speaker is always recommended.

To help defray expenses associated with running a US Support Group, the MDSF can provide monetary support in the amount of \$200.00 for startup funding. This provides an expense allowance for each Support Group to cover operating expenses, such as postage, copying costs, refreshments, or other related meeting expenses for your initial meeting.

Our members may have cancer-related financial issues. It is important for Leaders to remind their members about the financial assistance options which may be available to them. A Guide to Assistance Program in the United States is a resource that the MDS Foundation can provide upon request.

FREE LITERATURE

The MDSF will provide a supply of our literature about MDS, including booklets, treatment options guides and fact sheets to distribute at your meetings. Please remind your members that literature (in English and other languages) can be viewed or downloaded/printed from the MDSF website at <https://www.mds-foundation.org/patient-caregiver-resources/>. Some members may prefer printed copies of the publications. You can request copies of our publications as standard practice for your meetings. Please request your shipment of literature several weeks in advance of your meeting to give the Office time to ship it using standard postal rates.

LIABILITY ISSUES

In the process of leading MDS Support Groups, certain issues will arise that have an important liability consideration. The following is a discussion of common liability concerns.

As a Leader, you may be asked by members for advice about their medical situation. Leaders are not expected to have medical expertise and **should not give medical advice**. For example, you should not say, "It seems like [name of drug] might be a good option for you." Even with the best intentions of remaining objective, it is possible to lead someone toward a specific treatment. You may be held liable if your unintended advice results in negative consequences. At meetings, it is helpful to state the disclaimer, "I am not a doctor and cannot give you medical advice." When someone is asking for help with a medical situation, as Leaders, we listen carefully to their concerns. We may then suggest a second opinion, or we can open the question up to the Support Group to share their experiences with a similar situation. It is important to emphasize that everyone is unique, and what works for one person may not work for someone else. You can also direct the member to the MDS Foundation's Patient Liaison at patientliaison@mds-foundation.org. If a member wants to talk to another MDS patient about a specific treatment or special situation, the Leader can refer them to the MDS Foundation as well.

In an effort to keep our members informed, the educational component of our meetings may often include a discussion of clinical trials. As Leaders, we **cannot endorse or recommend any specific clinical trial**, but we can lead a discussion that is open-ended to include all current clinical trials. According to the MDSF Clinical Trial Policy, a company representative or researcher involved in clinical trials may not attend an MDSF Support Group meeting to provide updates and/or encourage participation in a **specific** clinical trial.

Confidentiality/Privacy Issues

The following guidelines are provided to assist you in various functions of your role as a Support Group Leader.

Support Group Member Lists – The list of members from the Affiliate/Support Group sent to the MDSF Office for inclusion in the MDSF database so that those members will receive MDSF services will be treated as confidential by the MDSF. In accordance with our policy regarding MDSF member lists, we will not give out names of members of our Support Groups to others including other MDS patient support groups or outside organizations.

Email Communication – When communicating with your Support Group members via email, please use the Bcc option to maintain privacy of members' email addresses. Within the Support Group, a member may want the names of people with MDS who live nearby or share a particular situation or treatment. With permission of the requesting member to share his/her email, send an email to the member(s) involved (Bcc) and ask if they would be willing to help the member in need. If so, they can communicate with the member seeking connection or assistance. It is not recommended to pass out the list to everyone in the Support Group – it is for the Leader only.

Individual Phone Communication – In your role as Support Group Leader, you may be contacted by MDS patients and/or caregivers seeking information and/or support. Initially during your conversation, confirm that all information discussed is confidential and only shared with the MDSF as needed and with permission. When contacting members on your list by phone, it is recommended not to leave a phone message about an MDS-related topic unless you are certain that family members are aware of the patient's MDS diagnosis.

Group Sharing – Group sharing is an integral part of the Support Group experience where members share personal health information and their concerns, feelings and experiences in living with MDS. Please remind members at the beginning of Group sharing that personal information shared in the discussion is not shared outside the Group.

SELF-CARE FOR THE SUPPORT GROUP LEADER

Ideally, when a person agrees to take on peer Leadership of a Support Group, she/he should have achieved a level of acceptance in living with and managing MDS that promotes an open and supportive discussion of the related issues and feelings. Anyone who has unresolved emotional concerns or the need to promote their personal approach to MDS in a directive manner should reconsider taking on the role of Leader.

In our role as peer Leaders, either an MDS patient or a caregiver/friend of an MDS patient, we are intimately involved with the issues that living with this rare disease encompasses. This peer relationship represents a powerful connection to our Support Group members in being able to personally relate to their needs and concerns.

The experience of being a Support Group Leader has its own personal rewards and represents generosity (generous/altruistic behavior), one of the major components of well-being. It is important for Support Group Leaders who are focusing on the needs of Group members not to neglect their own needs and take time for self-care activities that focus on overall wellness. Finding personal support is important through options such as connecting with others touched by MDS and other Leaders or even joining another Support Group, such as a local Leukemia & Lymphoma Society (LLS) group, as a member. Finally, sharing the responsibilities with a Co-Leader or members who can assist with specific tasks is an important consideration for some Leaders.





APPENDICES

(ADDITIONAL SOURCES OF INFORMATION)

MDS SUPPORT GROUP NEEDS/INTEREST ASSESSMENT

We are interested in your thoughts on the following topics to assist in planning Support Group meetings that will meet your needs/interests.

1. Please indicate your preference for day/time of meeting.
2. How often would you like to meet – times per year?
3. What is the longest distance you are willing to travel to a meeting on a regular basis?
4. How important is it for you to share experiences and feelings with other Group members?
_____ very important _____ somewhat important _____ not important
5. What educational topics are of interest to you, MDS-related and survivorship/wellness options?
6. What type of refreshment choices do you prefer – potlucks, light snacks or just beverages?
7. Do you have an interest in social activities as a Support Group meeting option?
If yes, please describe.
8. Other ideas?

Thank you for assisting us in planning.

MDS SUPPORT GROUP EVALUATION

In order to provide a Support Group experience that meets the needs and interests of our members, we are very interested in your thoughts about the experience.

1. Are the meeting times, frequency and location suitable for you? Yes or No (circle) If no, please explain.
2. Does the meeting facility provide a comfortable atmosphere? Yes or No (circle) Please explain.
3. Please share any suggestions you may have for future programs that are specific to MDS or more general in regard to wellness and survivorship.
4. If you were present at any meeting that involved a speaker, please comment about the experience in regard to the speaker's effectiveness and topic.
5. Is the Group sharing experience satisfying to you? Yes or No (circle) Please explain.
6. Is the amount of time devoted to Group sharing suitable for you? Yes or No (circle) Please explain.
7. Overall, how has the Support Group experience influenced your ability to live with MDS?
8. Any other comments or suggestions?

Thank you for sharing your thoughts.

SAMPLE LETTERS AND ANNOUNCEMENTS

Sample Letter – Welcome to our MDS Support Group

Dear _____,

It was a delight to speak with you. I want to “officially” welcome you to the MDS family. I fully appreciate that this is not a club you ever wanted to join, but one I hope you’ll come to cherish over time.

*The very first thing you should know is that **you are not alone**. Although getting diagnosed with MDS can at times be overwhelming and feel like you are on an emotional roller coaster, please know that the MDSF and our Support Group are here for you and your loved ones to help you understand your disease, research your options and offer education and support. Just call on us.*

I thought I would offer a few ideas for further support and education. In reaching out to the MDSF and your local Support Group, you have truly done so much already! Way to go on being your own best advocate!

- 1. We look forward to seeing you at future support group meetings. The next meeting is _____ (insert your meeting details here). We look forward to connecting with you again soon!*
- 2. If you have not done so yet, consider reaching out to the MDSF Office in Yardville, NJ at 1-800-637-0839. Their dedicated Office team can collect your full contact information and put you on the list to receive their newly diagnosed MDS Information Pack. They’ll also sign you up for their printed newsletter and e-news. Please know that these, and all of our MDSF services, are free of charge.*
- 3. Continue exploring the MDSF website, <http://www.mds-foundation.org>. In particular, look at the downloadable publications <https://www.mds-foundation.org/building-blocks-of-hope-downloads/> or watch their animated video presentations at <https://www.mds-foundation.org/you-and-mds/>.*
- 4. Consider joining the MDS Foundation Message Board where you can ask questions online to other MDS patients/caregivers to find out their experience. You can join on our website <https://www.mds-foundation.org/forums/forum/patient-message-board/>.*

5. Seriously consider coming to one of the MDS Foundation's Patient Forums. It is an amazing experience! A schedule of upcoming forums can be found here <https://www.mds-foundation.org/patient-and-family-forums/>. Copies of the slides and videos from some of the past presentations are on our website at <https://www.mds-foundation.org/patient-and-family-forums/#Previous-Patient-Forumsn>.
6. Have a question about a specific treatment or MDS topic? Good news! You can speak directly – from the comfort of your own couch – to the MDS Foundation Patient Liaison (an experienced and knowledgeable mentor). Email patientliaison@mds-foundation.org or call 1-800-637-0839.

As we discussed, I was diagnosed with MDS in _____ (insert a sentence about your story here, if appropriate). I'll never forget how reassuring it was the first time I walked into the MDS Support Group and met fellow members. It was a relief to meet others who share our disease. Kindly reach out if you want to talk anytime. I can be reached at: (insert phone number and or email here).

Warmest wishes to you and your family on your MDS journey,

Your Name & Signature Line Here



Support Group Letters/Announcements

The following documents are sample letters and announcements that you may find helpful in communicating your Support Group activities. At your request, the MDSF Office can send you a logo to use in your correspondence and communication. Please remember to use the logo in a professional manner, as you are a representative of the MDSF.

SAMPLE LETTER – SUPPORT GROUP LEADER INTRODUCTION

Dear Myelodysplastic Syndromes Patient or Caregiver/Family Member,

Myelodysplastic Syndromes (MDS) is a rare disease that can create feelings of loneliness and isolation. The MDS Foundation, Inc., offers Support Groups in many locations to help improve the experience of living with MDS.

As a person with Myelodysplastic Syndromes who has an interest in connecting with others, I am starting an MDS Support Group for MDS patients and caregivers/family members who live in (insert region). Our meetings will provide an opportunity to become more knowledgeable about MDS and to share experiences in the spirit of offering support to each other. At times, we may hear a guest speaker, watch a video or focus our discussion on a topic of interest.

If you think you would find this Support Group opportunity rewarding and would like to participate, please respond to me with your preference for meeting times: weekdays – daytime or evenings; or weekends. With enough positive feedback for starting a Support Group, I will be in touch with you regarding the details of our first meeting – agenda, location and date.

I look forward to hearing from you. Please call or email with any questions.

Sincerely,

Name

phone; email

SAMPLE LETTER – HEALTH CARE PROFESSIONALS

Dear Health Care Professional,

I am organizing a Myelodysplastic Syndromes (MDS) Support Group in (name of area) for patients/caregivers/friends, as a service of the Myelodysplastic Syndromes Foundation (MDSF). For more details about the MDSF, please visit the website at www.mds-foundation.org.

Your kind assistance in helping me promote awareness of this new Support Group opportunity among MDS patients is greatly appreciated. Myelodysplastic Syndromes is a rare blood disorder, and patients often struggle with feelings of isolation and lack of understanding about the disease. I plan to offer meetings regularly (every few months) so that support and a sense of community develops among members. Please share my news about this Support Group with your MDS patients and ask them to contact me at (email) or (phone) if they are interested or have questions. I would be happy to discuss this service with you at your convenience.

Thank you so much for your cooperation with this initiative to help improve the lives of MDS patients in our area.

Sincerely,

Name

Sample Meeting Flyer

SAMPLE FLYER

MYELODYSPLASTIC SYNDROMES (MDS)
SUPPORT GROUP

When confronting a major illness, loss or major life change, knowing that you are not alone is important.

JOIN US

Meetings are held the third Wednesday of every month, except as noted.

Refreshments will be provided.

Meeting Schedule
7:00 – 8:30 pm

January 15	April 22	July 15	October 21
February 19	May 20	August 12	November 4
March 18	June 10	September 16	December 9

Meeting Venue

Address
City, State, Zip Code

Our support group is open to individuals touched by MDS. The group is formed to give patients, families, and caregivers the support and strength to move forward together, rather than on their own.

For more information and to register, call

Tel: _____ or

Email: _____



SAMPLE LETTER – INITIAL SUPPORT GROUP MEETING

Dear MDS Patients, Caregivers, Family and Friends,

You are invited to join us for our first MDS (insert region) Support Group Meeting at (insert location, address, date, time). The meeting is an informal get-together to share experiences in living with MDS and ideas for future programs. Refreshments are provided.

(Insert parking information and specific meeting room.)

Please RSVP if you plan to attend and call or email me if you need directions.

Hope you can join us for this exciting new support/education opportunity for MDS patients in our area. I look forward to meeting you!

Thank you.

Leader name

MDS (insert region) Support Group Leader

phone; email

MDS FOUNDATION RESOURCES

Services Available to Members and Friends of the MDSF:

MDSF Patient & Caregiver Forums – These educational forums are held in different locations within the US and in other parts of the world to provide the opportunity for patients and caregivers to receive the most current information on MDS research and treatment options from leading MDS physicians/researchers (10 in the US and at least 1 Outside of the US annually). Medical presentations by MDS experts on a patient-level, specialty topics related to living with MDS, a Question and Answer segment and an important opportunity to network with other MDS patients and caregivers.

MDSF Newsletter (MDS News and MDS Minute) – The MDS News is a printed publication that features articles on the latest MDS research and treatments, Foundation activities, personal stories of MDSF members and Support Group news. The MDS Minute is a monthly electronic newsletter distributed via email.

MDSF Website (www.mds-foundation.org) – Our website is a valuable resource for MDS information and the services and support that the MDSF provides. It is often the first point of contact a newly diagnosed patient has with the MDSF.

MDSF Message Board – This online discussion group in English provides a forum where MDS patients and caregivers can communicate with each other about MDS medical topics or practical and psychosocial issues in living with MDS. For more information, go to <https://www.mds-foundation.org/forums/forum/patient-message-board/>

MDSF Directory of MDS Center of Excellence Physicians – a list of MDS experts (US and International) for second opinions at <https://www.mds-foundation.org/mds-centers-of-excellence-map-new/>

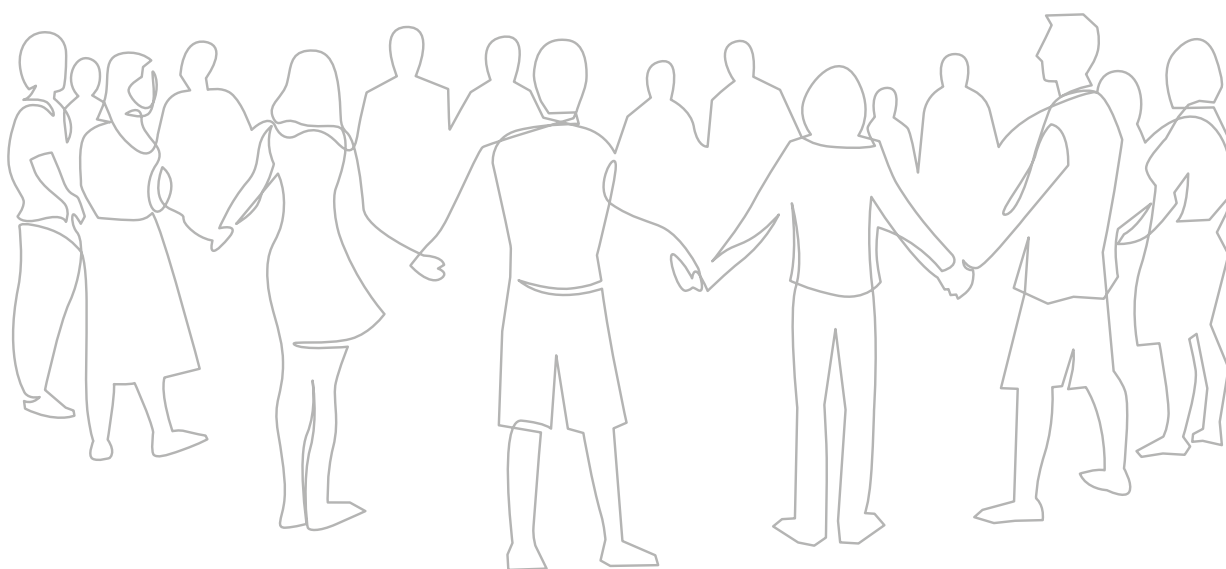
Support Group Network US and International Affiliates – MDSF Support Group Leaders and Regional Contacts are volunteers, either MDS patients or caregivers, who provide education and support to MDS patients and their families worldwide. A list of the location and contact information of MDSF Support Group Leaders and Regional Contacts can be found on the website at <https://www.mds-foundation.org/global-patient-support-groups/>

Information Packets for Patients and Medical Professionals – This is a comprehensive packet of information for the newly diagnosed. Information packets include user-friendly publications on the disease, treatment options, second opinions, selected videos from MDS experts and a list of MDSF services to help patients and their caregivers access the information and support to help them on their journey to live well with MDS. They are available on the website at <https://www.mds-foundation.org/patient-caregiver-resources/> to view, download and print, or can be mailed by request from the MDSF Office.

Patient Resources and handbooks that are available in multiple languages – These resources, developed in a collaborative effort with medical professionals, provide up to date MDS-related information for newly diagnosed patients and their caregivers. Most are available in languages other than English and can be viewed, downloaded and printed from the website, <https://www.mds-foundation.org/bboh/>

MDSF Presentations/Videos – Selected presentations and videos from our MDSF Animated Video Series and Educational Forums can be found on the website at <https://www.mds-foundation.org>

MDS Glossary – Commonly used bone marrow failure terms to know and help you understand new words that describe your disease and its diagnosis or treatment. <https://www.mds-foundation.org/wp-content/uploads/2016/04/9-27-17-MDS-Glossary-Update-Final.pdf>



[illegible]

*Thank you to Acceleron Pharma
for supporting this resource.*



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Email: patientliaison@mds-foundation.org