

STARTING A LOCAL MDS SUPPORT GROUP

MDS UK Guidelines



To all MDS patients, relatives, friends, nurses, haematologists and counsellors:

Since 2009, MDS UK has successfully set up regional support groups throughout the country to give MDS patients and families the opportunity to meet others with similar challenges, discuss feelings, gather information and socialise.

This would not have been possible without the cooperation from patients, relatives and nurses acting as contacts or local group facilitators. Their contribution has been invaluable to a small charity like ours and crucial for meeting the demand for face-to-face support from our members.

MDS UK is continuing to develop new groups by providing the necessary support, advice and financial means. But we need your participation. If you are interested in getting involved – please read the following guidelines derived from our experience in setting up, facilitating and coordinating local MDS support group meetings – and see where you could help out.

Thank you.

The guidelines below cover all the different elements and areas our organisation needs to consider when we start a new regional patient support group.

To help us set up a group in your area, we ask you to read these guidelines and instructions and identify where and how your skills and local knowledge could be best used.

Please let us know how much you are able to contribute to help set up and/or run such a group. Or please help us identify others who could also contribute – patients or hospital staff.

We know and understand you may not be able to commit long-term – but your initial help is necessary and essential. Creating a successful and thriving group does not happen overnight, as it takes time to find the right members and the right people who can help and share the various tasks. That's why we don't get frustrated at slow progress or lack of immediate volunteers. Neither should you.

Remember, not all of the elements listed below have to be in place to schedule the first meeting. Just tell us what you can contribute – and we will do our best to supply everything else. You know your neighbourhood – and have some local contacts. Please post/email us all your suggestions, so we can start working with you.

It may take several attempts to set something up – but don't give up trying. More patients will come through in time who may be willing to help out. Being part of a local patient group represents invaluable support for many people, for many reasons.

The strength and power of the patient voice and patient choices is now well recognised – and needs to be further established in some areas. Thank you for wanting to contribute to it.

**Call or email us for an initial chat.
We look forward to hear from you.**

MDS UK Team – Sophie, Monika, Peter

MDS UK Patient Support Group – Local Support Group Guidelines – February 2015

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GUIDELINES for regional support groups:

A. Planning the Meeting:

1. Locate meeting place:

- Explore different options locally: most libraries, churches and hospitals have meeting rooms that are often available free or at reduced costs to non-profit groups.
- Take into account: ease of access, availability of parking, transport links, hire costs.
- Inform us of any costs and dates – and put us in touch with the venue managers.
- Book early in advance – once you have our approval for costs and dates. We will settle the bills.

Note: Inform us ahead of time so we can reimburse all reasonable room hire costs.

2. Determine date and time:

- Choose a date and time convenient to most local members: ask about their preferences in advance. Some members may have scheduled appointments/treatments e.g. Azacitidine/ transfusions so try to work round them.
- Try to arrange the meeting a couple of months in advance as this helps with publicity, given that some MDS patients may only visit outpatient clinics every 2-6 months.
- Consider the advantages and disadvantages of meeting regularly at the same time/day or flexible scheduling.

3. Book guest speakers:

- e.g. specialist from one of the MDS Centres of Excellence, nurses, dieticians, transfusion staff, physiotherapist, counsellor. They will speak for free if you ask them.
- Ask one of the local members to prepare a talk/presentation about their experiences or a topic of special interest, relevant to MDS.

Note: Contact us to discuss your ideas or ask for assistance in identifying/booking guest speakers.

4. Use posters/flyers to advertise the meeting:

- Identify a local contact person (or people) whose contact details will be made public on the poster/flyer. The local contact person will be required to record pre-registrations and attendance and answer basic questions about the meeting e.g. starting time, details of the guest speakers, nearest train station etc.
- Design your own poster/flyer using our poster template.
- Take posters and flyers to your local hospital(s) to have them displayed in the waiting area.
- Place posters or flyers in doctors' offices, pharmacies, libraries, church halls, grocery stores etc.

Note: We will design posters and flyers. Contact us to order the materials or ask us to post them to your local hospital(s) directly. We can also take pre-registrations for meetings to support you at the early stages of starting a new support group.

5. Publicise the meeting:

- Inform other MDS patients, known to you, about the meeting.
- Ask clinical staff at your local hospital(s) to inform all their MDS patients about the meeting.
- Advertise the group in local newspapers. Most newspapers have a health section with a datebook, calendar or an area for support groups. It's a free service the paper offers.
- Get local newspapers and health periodicals/journals to write articles on Myelodysplastic syndromes.
- Local hospitals have a health calendar: call hospitals and get on their list of support groups.
- Post information about the group on the MDS UK Forum and MDS UK Facebook page. We will advertise your Group and all your meetings on our website.

Confidentiality: We will inform all our local members and clinical contacts about the meeting in advance. These contact lists are confidential. Please tell us if you would like to add a contact to our list or if you would like to start your own local members and/or clinical contacts lists. **IMPORTANT:** If you do keep your own lists of attendees, you must not share information with other MDS patients, relatives or clinicians without the express permission of the patient. You must also liaise with MDS UK regarding any changes to your local members and/or clinical contacts lists.

6. Gather necessary materials for the meeting

- Keep a list of patients and relatives pre-registered to attend the meeting. Always check whether they are new or existing members of MDS UK Patient Support Group. Any new member should be instructed to call our main office before attending any local meetings.
Use this list to plan refreshments and information materials.
- Provide us with a price list or quote for necessary refreshments e.g. tea, coffee, biscuits or pre-order catering, if available at the meeting place. After we approve the costs – please order items according to anticipated number of attendees. We will either pay the bill or refund you those expenses.
- Contact us to order information materials for your meeting e.g. our newsletters, factsheets, leaflets etc.
- Identify other helpful information materials available in Macmillan and other Cancer Information Centres.
- Contact us to order name labels, pens, notebooks or any other required stationery.
- Contact us to receive our Attendance Register template. Ensure every attendee registers their attendance on the sheet upon arrival.

Note: *If you need to purchase any materials/refreshments or use catering please inform us ahead of time. We will need to approve the costs and settle the bills. Please also keep any receipts. We will reimburse reasonable expenses if given prior notice..*

B. Suggested Format for the Meeting:

You may select a group facilitator (or facilitators) in advance. Our staff will be happy to assist you especially at the early stages of starting a new support group. The facilitator will introduce him/herself, welcome everyone to the meeting, inform about the available facilities and outline the agenda for the day.

Those in attendance will then be asked to introduce themselves. Sufficient time should be allowed for a round-up of patient introductions. This is the most important part of the meeting, which will allow the attendees to get to know one another and identify commonalities and shared experiences.

We recommend to schedule a short break (15 min) half way through the meeting e.g. between the patient introduction and a guest speaker presentation.

After the break, the facilitator will introduce the guest speaker who will provide a short presentation on the topic of interest to MDS patients and relatives. Reserve time for a question and answer session with the speaker immediately after the presentation. If you are inviting a clinician, please ask members to keep their questions general and not specific to their own MDS to keep the conversation interesting to everyone present. These Q&A sessions must not turn into private consultations.

Alternatively, you may want to hold the meeting without a speaker – as an opportunity for all of you to meet, exchange experiences and support one another.

The very first meeting will be facilitated by MDS UK staff, who will provide a short presentation about MDS UK, the programmes and services available, and the structure and benefits of forming a local Support Group. When possible, MDS UK staff will attend subsequent meetings too.

Don't feel all elements have to be in place to hold this first meeting.

The main purpose of the initial meeting is to decide how to progress the group – and how to build on it.

Hold a facilitated question and answer period following this presentation. Issues that you will want to cover include:

- What are the main areas the Support Group should concentrate on? For instance:
 - Information forums
 - Support meetings
 - Assisting individuals to access services
 - Fundraising to help raise funds for research and patient services
 - Public awareness events
 - Buddy Scheme – very useful for newly diagnosed patients/family members

- Who is available to assist with organising/conducting these services and events?

After the participants have decided to form a group, identify a volunteer or group of volunteers willing to take on a more active role in maintaining the group and planning future meetings.

C. Support Group Facilitator(s): Description of the Role

Overview: 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. This role can be shared by 2 or 3 people.

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 feedback and information to the MDS UK Support Group for newsworthy items, as required.

Suggested time required:

- One meeting every 2-3 months (approx. 2-3 hours)
- Speaker coordination (approx. two hours/month)

Optional Additional Meeting Activities:

- Hold sessions for caregivers to discuss their issues, concerns, frustrations and share ideas for rest, relaxation and coping with stress.
 - Organise a respite day for caregivers, social outings and gatherings.
 - Arrange for volunteers or fellow caregivers who are willing to share caregiving responsibilities in order to relieve others.
 - Discuss available resources -- government programs, transportation, respite programs, community hospices, life insurance.
 - Discuss the fear of dying and coping with what lies ahead both for the client and his/her family.
 - Discuss research updates (invite a haematologist, researcher or drug company representative).
- (Note: Caution the speaker not to recommend a certain therapy or drug to individual/s.)*
- Hold a video/book review evening. Ask participants to review a book or video and present to the group.

D. Support Group Evaluation

Ongoing evaluation of a Support Group is imperative to keep it fresh and up-to-date. When you pick a speaker and topic for a meeting discuss the objective with the speaker then set some goals for what information is to be imparted. From those goals, develop a quick evaluation form to be completed at the end of the meeting. This feedback will help to set the agenda for the next meeting which covers this topic.

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 above topics will be appropriate for all participants. For instance, talking about death and dying may upset newly diagnosed and younger individuals.

The MDS UK staff will attend the first meeting and will assist with on-going advice and support throughout the existence of the local group, as well as covering all reasonable necessary expenses.

MDS UK can also put you in touch with group moderators who have been running their group for some time – they can provide valuable additional comments and advice.

Thank you for taking the time and the effort to help us help other MDS patients.

Your contribution is crucial to our work!

E. Organising an MDS Patient Support Group Meeting – Checklist

Use this checklist as a step-by-step guide to your preparations for the meeting - in conjunction with the detailed suggestions enclosed in sections A, B & C (references to relevant sections provided in brackets).

Please remember to inform us in good time regarding any decisions, payments and of course for us to be there.

Make notes – such as what you need to ask us, what you want us to complete, who else you need to talk to etc.

	Responsibilities:	Your notes:
Before the meeting		
<input type="checkbox"/>	Locate and book a meeting place (A.1)	
<input type="checkbox"/>	Determine meeting date and time (A.2)	
<input type="checkbox"/>	Identify and book guest speakers (A.3)	
<input type="checkbox"/>	Prepare the poster, flyer (A.4)	
<input type="checkbox"/>	Advertise/Publicise the meeting (A.4 & A.5)	
<input type="checkbox"/>	Gather necessary materials (e.g. information resources, stationery) (A.6)	

<input type="checkbox"/>	Plan refreshments (A.6)	
<input type="checkbox"/>	Prepare agenda (B)	
<input type="checkbox"/>	Select meeting facilitator (B)	
At the meeting		
<input type="checkbox"/>	Record attendance, give out name labels (A.6 & B)	
<input type="checkbox"/>	Present the agenda, inform about the available facilities e.g. toilets, refreshments (B & C)	
<input type="checkbox"/>	Coordinate speakers (B & C)	
<input type="checkbox"/>	Collect feedback and evaluations from attendees (D)	
After the meeting		
<input type="checkbox"/>	Pay outstanding bills and liaise with the room provider, catering services etc. - as required	
<input type="checkbox"/>	Send the completed attendance sheet to the main office	
<input type="checkbox"/>	Provide MDS UK with brief feedback on the meeting (report any concerns, request further information, share helpful advice)	