

How to Develop a Mutual Support Group



multiple sclerosis
international federation

The Federation's Aims

Established in 1967, the Multiple Sclerosis International Federation links the work of national MS societies worldwide. We are committed to working together and with the international research community to eliminate MS and its devastating effects. We also speak out on a global level for those affected by MS.

Our priorities are:

- To support Member MS Societies in their goal of enabling full integration of people with MS and their carers to live their lives to their fullest potential
- To stimulate global shared research into a cure for MS and the alleviation of its symptoms
- To stimulate the active exchange of information on best practice amongst Member Societies and the wider MS community
- To provide support for the development and increased effectiveness of new and existing national MS societies

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Foreword

Mutual Support is based on the concept that people who share common experiences can provide one another with emotional support, fellowship and information. For people with MS and their families, Mutual Support Groups offer the opportunity to exchange experiences and to give and receive support, information and encouragement.

The idea of creating a work group within MSIF specifically focused on the topic of Mutual Support began as a conversation within the Individual and Families Services Committee in 1997 in Buenos Aires, Argentina. Since then a great deal of work has been carried out by many people who enthusiastically completed questionnaires, responded to telephone interviews, participated in conference calls and pilot studies and provided feedback, advice and moral support. The results of these efforts is this booklet and the fact that many, many people have been convinced, along the way, of the great potential of Mutual Support for people with MS.

The promotion of Mutual Support Groups on the part of MS Societies, healthcare professionals and people with MS will undoubtedly carry this movement beyond any individual or cultural barriers.

Michele Messmer Uccelli, The Italian MS Society

Introduction

The aim of this booklet is to help you start and run a Mutual Support Group (MS Group) for people with MS. MS Groups are called different things in different countries such as Self-Help Groups and Peer Support Groups.

One of the ways in which people with MS find support and information is when they meet with others in similar situations as themselves. An MS Group provides an opportunity for such meetings to occur.

There are many different kinds of MS Groups. No one kind is necessarily better than another. What matters is that they are helpful to those who take part.

When you start a group, you will want to find an approach that is most appropriate for you and the other members of your group. You may use the ideas in this booklet as a starting point, or you may have your own ideas.

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Confidentiality

This is very important if people are to feel free to talk about their situation openly. People will be concerned about whether what they say in the MS Group will be talked about outside. What this means is that everything said must be treated as confidential. You may not think something is confidential, but the person talking may see it as a very private matter. Any information, which might individually identify a group member, cannot be released outside the group and can only be released within the group with the express consent of the individual.

It is imperative that everyone in the group feels that they can say anything, reveal anything, or talk about anything and know that their words will stay in the group. When confidentiality is acknowledged and implemented, an atmosphere of trust is established and members can really feel free to share openly.

Anyone not in the group or involved in the discussion is an outsider. This means your spouse, your best friend, professionals you may want to consult, salespeople who may ask for names of people in the program, people from the media, etc. If at any time you wish to violate the rule of confidentiality you must ask the individual(s) for permission.

As an example, you may say "Someone I know said."
You should not say "John from my MS Group said."

Other points to remember

- Do not release the name, address, e-mail address, fax or phone numbers of group members to anyone outside the group.
- Information about community resources, which might benefit an individual, can be shared in the group. It is up to the individual to contact the resource. Do not contact the resource or give the name of the individual to the organisation on their behalf.

Program Limits

There are also limits to what the MS Group can do. Each person must accept responsibility for his/her own physical and mental health. MS Groups are not a substitute for psychotherapy or counselling. An MS Group differs from a therapeutic group led by a professional in that its reliance is on its members for support, rather than a therapist. Although MS Groups work with professionals, the role of the professional is complementary rather than central. This means getting help outside the program if needed. If in a crisis, the individual is responsible for getting the necessary therapy or medical care. People within the MS Group can only provide support.

“Peer support is contagious!”

What is a Mutual Support Group and what can it do for you?

A Mutual Support Group is a gathering of people with MS. The purpose of the group is to provide support to the members and thus allow them to cope better by:

- sharing their feelings and experiences
- learning more about MS
- obtaining accurate information
- giving people with MS an opportunity to talk through problems they are facing or choices they have to make
- listening to others who share similar feelings and experiences
- helping others through the sharing of ideas and information and providing support
- knowing they are not alone

The roles of an MS Group are mutual support and information but it can serve to identify professional help.

What it cannot do

An MS Group cannot solve all problems, nor can it replace the services of a doctor or other healthcare professionals. It is important to remember that an MS Group is not helpful to everyone. Some people are not comfortable sharing personal feelings with others.

“My group can’t replace the support I get from my family, but it is so great to talk about things I’m going through that my family just can’t understand.”

Types of MS Group

Some MS Groups develop with characteristics in common. The most important factor is that any decision to develop MS Groups with particular members should be a decision made by the group. Examples include:

- newly diagnosed
- women
- men
- different ages
- couples

In addition, MS Groups may also be developed for spouses, carers and family members of people with MS, following the same basic steps outlined in this booklet.

How to get started

If it appears that there is no suitable group in your area to meet your particular needs, you might consider the following questions before starting.

First ask yourself:

- do I have the necessary time and energy?
- do I have the needed support from family and friends?
- can I cope with the additional demands of organising a support group?
- do I wish to hear about other people's experiences and to share my own?

Getting help

Don't try to do it all yourself. Are there other people with MS you can talk to? Will they help you share responsibilities?

Are there local or national organisations that might help, for example, a national MS Society or local branch?

If there is an MS Society in your country they should be contacted about forming the MS Group as they could also help identify professionals, advertise the MS Group and provide support. Your local MS branch or society contact is _____

Are there any professionals, doctors, social workers, health workers, nurses etc. who might help by:

- spreading the word about the group?
- serving as invited speakers on various topics?
- providing information about MS?

Planning the first meeting

Getting started can take some planning and effort. The following are some of the issues to consider when preparing for the first meeting:

Aims of the group

It is a good idea to work out what the aims of your group might be. This will help you in explaining your ideas to others and enlisting their help. Group members should review these aims once the group is formed.

Aims can be very simple such as:

- to provide people with MS with an opportunity to learn more about the disease
- to enable people with MS to meet on a regular basis to provide mutual support
- to enable people with MS to meet others in a similar situation and share their feelings and experiences

Who might be in the group?

An MS Group is not for everyone, but many people with MS find them helpful.

Publicising the meeting is important in order to recruit those who might be interested in taking part.

The following are a few of the many ways to advertise a meeting:

- the national MS Society magazine or newsletter
- radio and television stations often provide free advertising for community events
- local newspapers often publish notices of meetings, check first to see if there is a charge for this
- places of worship are also a good source of new members, mention might be made of the meeting in their regular bulletin or notice board
- posters can be placed in doctors' offices, community centres, nursing homes, libraries, pharmacies, and food stores
- by word of mouth

There may also be others that are specific to your community.

Any publicity should include:

- date, place and time of meeting
- name, telephone number, or place where a contact person can be found

Numbers

It is probably best not to worry about the numbers at first. It will be impossible for all members to attend every meeting, but some level of commitment is necessary. Attendance may also drop after the initial meetings. If the numbers become too large and it becomes difficult for everyone to participate, then dividing into two groups might be considered. Do not be upset about too few people attending the first meeting.

Open or Closed

During the first meeting it should be decided by the MS Group whether it will be an open or closed group. An open group will allow new members at every meeting whilst a closed group will consist of those people who attended the first few meetings only. Once the decision has been made it has to be kept. If, after three months, this method develops problems then it can be revised.

Place

In selecting a place to hold the meetings you might want to consider:

- accessibility – is the location and its facilities fully accessible?
- convenience – can people get there easily?
- size – is it large enough? Is there enough space for wheelchairs and are there enough chairs?
- comfort – is it quiet and private enough to allow for a comfortable exchange between group members?
- cost – is there a charge for its use?

Schools, places of worship, community centres, libraries or someone's home can be considered.

It is essential for someone to visit the place where a meeting is to be held beforehand, to inspect it and be sure that the above considerations have been met.

Time

How often? Monthly? Every two months? Usually members of the group will make this decision at the first meeting. Most groups meet on a regular basis. It is easier for everyone to remember if the day of the week and the time are the same for each meeting.

The frequency of the meetings should be reviewed on a regular basis.

What time? Morning? Afternoon? Evening? It all depends on what is convenient to members of the group.

A note about choosing a convenient time – it is impossible to find a time that is always convenient for everyone. However, if members exchange telephone numbers, a member who is unable to attend a meeting still has a way of being in touch with others.

Cost

MS Groups should be free of charge. Finding a free room and having members take turns bringing refreshments is a good idea. If you do end up with expenses, it is usually preferable that these are paid for by the group, not by one or two individuals.

If you have a national MS society, it or its local branch should be approached for financial assistance.

Recommendations

- The group should decide how often to meet, how long the meeting will last and for how many months (e.g. the group could meet once a week for a period of 3 months and each meeting could be 90 minutes in duration). This decision should be reviewed by the group on a regular basis.
- A member of the group should keep track of the time to make sure that the meeting starts promptly and does not go on too long. The length of the meeting should be agreed beforehand.
- After 3 months the group should evaluate whether or not it is possible and useful to continue. At this time new members can be invited to participate.
- Remember that all groups must eventually come to an end. The participants themselves need to decide when the group no longer offers clear benefits to the members. This is not a sign of failure, but an accomplishment!

The first meeting

It is important to consider the purpose of the meeting and ask 'why are we here and what do we hope to accomplish?'

- is it for support only?
- is it to provide information?
- is it a combination of support and information?
- does the MS Group need a name?
- should there be invited speakers?
- for how long should the group be in existence?

Practical arrangements

Having the right environment where participants feel welcome and comfortable is important. You may wish to consider the following as you prepare for the first meeting:

- arrangement of the room – are the chairs in a circle to help create a friendly atmosphere?
- temperature of the room – is it too hot or cold?
- welcome person – has someone been given the task of greeting members as they arrive and to make sure they are made to feel welcome?
- someone needs to know how to make contact with all the members of the group
- resources – are there any booklets or pamphlets to be displayed which may be of interest to the group?

Choosing a group leader

The leader of the group will be one of the group members. This may be the most important decision you will make in setting up your group. The role of the leader is vital to the success of the group. A leader must be comfortable speaking in front of a group and have the ability to:

- encourage participation and ensure all members who wish to get a chance to take part do so
- ensure that the rules agreed to are respected
- identify if a particular individual may require more support and assistance than the group is able to offer
- communicate with members to confirm date, location and time of meetings

Do not overlook the fact that the leader may also require support. Leading a group can be emotionally draining, so being able to talk to someone else about this is crucial. Maybe the leader could talk to other leaders of other MS Groups or to someone at the MS Society.

Topics for meetings

This will help the group keep focused and efficiently use the time available, allowing everyone the chance to speak.

- With one participant writing, the group should brainstorm and list ideas for topics they would like to discuss in the upcoming meetings. Every idea should be written down, no matter how strange it may seem.
- Once a long list of topics has been made, go down the list, topic by topic, and take a vote, by a show of hands, on which topics are of more interest to the group. Agree that if a topic doesn't receive 6 of 10 (or 5 of 8) votes it is removed from the list.
- Continue this process until 12 topics remain on the list (3 months worth of topics).
- If it seems logical to rearrange the order, the group should do so.

Ideas for group discussion

- experience of diagnosis
- telling others you have MS
- family issues
- employment issues
- dealing with specific symptoms related to MS
- planning the future and dealing with unpredictability
- relationship with your doctor
- therapy choices

It is possible for...

- The leader or members to invite someone from the MS society or even a neighbouring country's MS society to speak about its aims, services and plans.
- The leader or members to invite a healthcare professional (doctor, physiotherapist, psychologist, social worker) to discuss a specific therapy, medication, or symptom.
- Meetings to be held on mobility devices, equipment resources, adapting the home, workplace, etc.

During the course of the MS Group meetings, a member of the group can request a substitution in a subsequent topic agenda. This may be due to the fact that topics are chosen before group members are comfortable enough with one another to suggest discussion of more personal topics, such as sexuality and intimacy. Any such requests can be directly proposed to the group or can be related to the group leader anonymously to be proposed to the group, which should vote on making the substitution.

“During the first meeting everyone was really serious and we decided topics that wouldn't offend or embarrass anyone. It only took us 2 meetings to cut through the politeness and admit out loud that there were important topics that we were too shy to mention during the first meeting when we voted on topics. We all agreed to substitute accessibility issues with sexuality at the next meeting!”

Basic rules

Early in the life of a group, it is important for the group to agree on some basic rules. These help members develop a sense of trust and allow them to more easily share their feelings and experiences.

The group should ensure that:

- all information about members and discussions within the group is kept confidential
- members of the group listen and support each other without criticising or making judgements
- each member is respected and all are made to feel equal in the group
- each member has a chance to speak
- what is right for one person may not be right for another

The regular meeting

To assist the flow of the meeting it may be helpful to set aside a specific amount of time for each part. It will be up to the leader and group to determine the order and the time for each part.

The group leader could begin each meeting by

- asking all members to introduce themselves
- as people with MS are likely to be from different backgrounds with varying levels of comfort in sharing personal information it is important that members are greeted in a friendly way and made to feel comfortable and welcome
- stating the purpose of the group
- reviewing the rules
- sharing any information about events that may be of interest to the group
- asking members to share information that may be of interest to the group

Beginning the discussions

The group leader may begin a discussion by talking about personal experience of the chosen topic and asking members for their reaction or to share experiences. Others should then follow the leader's example.

“No one seemed to know what to do, but as soon as the leader introduced himself and started to talk about when he was diagnosed and how hard it was to talk to his family, we all just took our turns and followed his example. It wasn't easy at first, but now we're all pretty comfortable with each other.”

Summing up

When it is time for the meeting to end, the leader may ask one, two or several members to share their thoughts regarding the meeting. The leader may also wish to summarise the discussion and ask the members if they agree with his/her impressions. The date and time of the next meeting should be decided upon or announced.

Keeping the group going

It is a good idea to review, on a regular basis, how the group is working. The needs of people with MS and caregivers change and it is helpful to ask members such questions as:

- is the meeting place, day and time convenient?
- do you feel welcome?
- do you have the opportunity to say what you wish?
- do you find the meetings helpful?
- do you think members are made to feel welcome?
- how can we improve the group?
- what topics would you like to see addressed?
- should the group size be controlled?

Potential Problems

Any group can experience moments of difficulty, like when one person tries to monopolise the discussion, or when it seems that nobody wants to make a comment and there's that uncomfortable silence or when someone raises a serious matter that cannot be handled by the group, such as a physical or mental health issue. Below are a few phrases that you could use in these moments of difficulty.

Encouraging discussion

- why doesn't someone share an experience they've had on this issue/in this situation
- it seems that we're leaving something out/missing something

Keeping the discussion focused

- can't we try to be more focused in our comments?
- we're off on a tangent again, let's try to get back to the point
- we don't have enough time to stray from our main topic
- maybe we've discussed this long enough, shall we move on

When someone is monopolising the discussion

- everybody needs to give his/her opinion
- let's not make this a one-sided discussion, everyone should give input.

When someone raises a serious matter that cannot be handled by the group

If a situation arises that requires attention outside the group it is important for the group leader to talk to the person one to one after the meeting and encourage professional intervention. It may be that the liaison person of the national MS society or its local branch could handle the situation. If the group is uncomfortable with such a situation it should be dealt with straight away.

“Someone from the group mentioned that they were aware of an abuse situation with a friend with MS who was bedridden. The group leader told the person that she didn’t think it was good enough to discuss it during the meeting but that we needed to let someone know. We all agreed to call our contact person at the MS Society for advice.”

Sometimes it just helps to take a break when the group is at a difficult point. During every meeting there should be at least one break of 5-10 minutes.

REMEMBER...

The group is your own so feel free to do what you’d like to make it more creative, for example playing music before meetings, taking turns bringing snacks, etc.

“It is one of the most beautiful compensations in life, that no man cannot sincerely help another without helping himself.”

Ralph Waldo Emerson (1803-1882)

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