



National  
Multiple Sclerosis  
Society

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# Guidelines for Managing Self-Help Groups

A Manual for National MS Society  
Self-Help Group Leaders

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“It is one of the most beautiful compensations of this life that no [person]  
can seriously help another without helping [themselves].”

Charles Dudley Warner 1873

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## INTRODUCTION: OVERVIEW AND RATIONALE

Self-help groups bring together people who share a common life experience for support, education and mutual aid. The benefits of self-help groups to their members include:

- Learning new information and strategies for confronting problems
- Finding reassurance and support from others with similar life experiences
- Developing personal insights and achieving personal growth
- The opportunity to be helpful to others
- Learning to express feelings better and to be more sensitive to the feelings of others
- Feeling empowered and more self-confident in coping with challenges
- Developing a connection to a community, personal identification with a social group and less personal isolation

Self-help groups are critical to service delivery in the National Multiple Sclerosis Society.

Self-help groups of the Society:

- Are a service provided by chapters
- Provide a community presence for the Society
- Serve as a resource for the chapter
- Provide the chapter with a network to disseminate information and resources

There are nearly 1200 Society affiliated self-help groups across the United States representing some 30,000 people with MS, family members and friends. The Society recognizes the valuable role self-help groups can play in addressing the informational, emotional and social support needs of our members and in achieving the benefits described above.

While self-help groups are beneficial to most members, the potential for negative effects and problematic issues also exists. Implementing the training recommendations and practices described in this manual will minimize the potential for problems, maximize the many benefits of National MS Society self-help groups and strengthen the relationships between you and your chapter.

A note on terms: The terms self-help group and support group are used interchangeably by many people. Within the Society, self-help groups are considered those groups that are peer-led, with members being people who share the similar experience of being affected by MS. Support groups, in contrast, are typically led by professionals. Social groups are also available across the Society and focus more on social time and networking for peers and group members.

## NATIONAL MS SOCIETY STANDARDS FOR SELF-HELP GROUPS

The following standards for self-help groups are based upon established principles and practices from both within and outside the organization. It is the intent of these guidelines to offer clarity and guidance to self-help groups and to strengthen the partnership between our volunteer leaders and the organization. We recognize and value the role self-help groups play in supporting the mission, especially in improving the lives of people living with MS and the many highly successful chapter/volunteer partnerships we have across the country.

Chapter staff, group facilitators and group members themselves share responsibility for upholding these standards and must be willing to commit to:

- Provide accurate and appropriate information
- Empower group members
- Represent the Society positively
- Provide feedback to Society staff
- Be responsive to the needs of the Society
- Adhere to Society guidelines

The list of standards for self-help group leaders follows here.

### **1. INDIVIDUALS WHO SERVE AS SELF-HELP GROUP LEADERS POSSESS SKILLS AND ATTRIBUTES TO EFFECTIVELY ORGANIZE AND LEAD A SELF-HELP GROUP.**

These skills and attributes should include:

- Willingness to maintain a close working relationship with Society staff and to be a team player
- Ability to work with minimal supervision from staff
- Personable, empathetic and welcoming personality
- Participation in on-going education efforts
- Willingness to learn about and promote National MS Society programs and events
- Strength in the areas of communication, group facilitation, organization and management
- Dedication to the Society's mission, and a desire to make a difference for those living with MS
- Openness to learning new ideas and approaches to group management strategies
- Personal relationship with MS
- Ability to empower and motivate group participants

- Knowledge of and access to Internet/e-mail technologies and equipment
- Engagement in, or support of, organization-wide activities (e.g., Walk MS<sup>®</sup>, MS Awareness week, advocacy, etc.)

Group leaders are most often persons with multiple sclerosis or persons with a family member that has multiple sclerosis. Some groups are led by a professional (e.g., social worker or nurse). Whether leaders are volunteers with MS or paid professionals, they engage participants in developing the group focus and planning meetings.

Chapter staff provides job descriptions for self-help group leaders and leaders work within the parameters of the description. (See Appendix A.)

It is critical that self-help group leaders understand what is expected of them.

Job description should include:

- Tasks the group leaders are expected to perform (responsibility)
- Parameters within which they work (authority)
- Goals oriented toward results (accountability)
- How the leader will know if he/she has achieved the results (measurement)
- Information about the Society's confidentiality and code of conduct policies

Staff may develop “cooperative agreements” to be used with group leaders and members that specify the rights, duties, and responsibilities of the chapter and group; and the chapter and leader. Such agreements are most effective when they support these basic standards and are developed in collaboration with group leaders themselves.

## **2. ALL ACTIVE SELF-HELP GROUP LEADERS WILL PARTICIPATE IN STRUCTURED ORIENTATION AND ON-GOING TRAINING OPPORTUNITIES**

Training for all facilitators is essential to maximizing the positive benefits of self-help group operation.

New leaders — Prior to an individual assuming responsibility for facilitating a self-help group the individual must participate in and complete the central training designed for all new group leaders of the Society.

All leaders — It is essential that all leaders participate in Society-sponsored training to maintain leadership skills, understanding of Society resources and receive updates on current research on MS.

It is the responsibility of the self-help group leader to successfully complete all required trainings, and for chapters to establish procedures for promoting training opportunities and monitoring and tracking training participation.

Self-help group leaders must participate in at least two centralized training opportunities during the fiscal year. These trainings will be scheduled by the Society's home office and managed and promoted centrally.

### **3. SELF-HELP GROUPS OPERATE IN ACCORDANCE WITH NATIONAL MS SOCIETY POLICIES.**

Policies described within include:

- A. Confidentiality
- B. Code of Conduct
- C. Accessibility
- D. Non-Discrimination
- E. Do Not Provide Medical Advice
- F. Do Not Provide Medicine Sharing
- G. Affirming Life
- H. Fiscal Responsibility and Fundraising Policies
- I. Background Checks
- J. Do Not Provide Transportation to Members
- K. Require Waivers for some Group Activities

#### **A. Confidentiality**

***Self-help group leaders and participants maintain confidentiality.***

- Identification or personal information revealed in a group meeting is not to be disclosed outside of the meeting or the National MS Society unless the participant is in risk of personal harm.
- Disclosing identifiable information, photos or videos must have the individual's written authorization. See Appendix D.
- Participant group lists are voluntary, not obligatory, and may not be distributed outside the self-help group and chapter.
- All Society-affiliated self-help groups are programs of the National MS Society. When individuals participate in a Society self-help group, group leaders are expected to share group membership information with chapter staff. This is not a breach of confidentiality.



Confidentiality policy may be found in *Managing Chapter Programs and Services 2012 Update: A Desk Reference for National MS Society Chapter*. See your chapter liaison for a copy of policies listed here.

## **B. Code of Conduct**

***Self-help group leaders will follow the Society's Code of Conduct policy.***

In the event that a volunteer's or staff obligation to operate in the best interests of the Society might conflict with his or her personal interests, or with the interests of any organization in which they have an interest, financial or otherwise, or with which they are affiliated, they shall disclose such conflict and any and all relevant information as soon as they become aware of it, shall absent themselves from any relevant deliberations, and shall refrain from participating in decision making in connection with the matter.

## **C. Accessibility**

***Self-help groups meet in accessible places of public accommodation.***

It is a National MS Society standard to conduct official functions only in public accommodations that meet Americans with Disabilities Act (ADA) accessibility standards.

Meetings must be held in public locations that meet National MS Society accessibility standards. These accessibility standards are found in *Accessibility Site Checklist for Programs and Events: A Manual for National MS Society Chapters (2009)*. Ask your chapter liaison for a copy or further guidance.

Self-help group meetings should be held in public facilities and ideally these locations carry public liability insurance. In general, because of both liability and accessibility concerns, private homes are not appropriate locations for group meetings.

## **D. Non-Discrimination**

***Self-help groups abide by the non-discrimination policies of the Society.***

Self-help groups accept new members into their groups on an ongoing basis, provided the individual is appropriate for the group. Individuals from for-profit companies whose intent is to derive financial or secondary benefits from group participation are not appropriate for regular group leadership or membership.

Chapters may offer groups with a special focus (e.g., a group for working people, a carepartners group, a group for people “mildly affected”). However, groups must uphold the Society’s non-discrimination policy. (See appendix E.) A group may not, for example, have a “no wheelchairs allowed” policy, even if their focus is dealing with invisible symptoms. Chapter staff may help special interest groups to maintain their focus by providing guidance to individuals and helping them to find groups appropriate to their circumstances and interests.

At the discretion of chapter staff, there are certain circumstances where a time-limited, “closed” group is appropriate. For example, participants in a program for the newly diagnosed may choose to continue to meet at the conclusion of the series for a specified time period. In such circumstances, the chapter could sponsor the group, but not promote the group to others.

#### **E. Medical Advice**

***Self-help group leaders do not give medical advice.***

In their role with the National MS Society group leaders do not offer medical advice even if they are healthcare professionals by trade. Group leaders and members may share information on personal experiences, treatments, etc., but refrain from giving personal interpretations, giving advice, sharing medication or offering recommendations.

In order to help ensure that advice is not given by group members, group leaders share group guidelines at all meetings, monitor discussions and lead the group process.

#### **F. Medicine Sharing**

***Self-help groups do not engage in sharing or swapping medicines of any kind.***

For liability reasons, National MS Society staff and volunteers cannot get involved in any swapping or sharing medicines among group members. Many prescription medicines are controlled substances and FDA regulations do not permit sharing medicines among patients because the safety and efficacy of shared medications cannot be ensured. Therefore, group leaders must not permit the practice or communication of shared medications to happen during any Society group meetings.

## **G. Affirming Life**

***Self-help groups support National MS Society policies affirming life.***

Group leaders must alert chapter staff of the potential danger for individuals doing harm to themselves or others. Group leaders must alert chapter staff if abuse or neglect is suspected. Imminent threats to life should be reported to chapter staff, appropriate social service agencies or law enforcement immediately, or as urgency dictates.

Chapter staff is responsible for providing self-help groups with training and materials that describe the Society's positions and policies on suicide, assisted-suicide, abuse and neglect.

## **H. Fiscal Responsibility and Fundraising Policies**

***Self-help groups comply with National MS Society fiscal policies.***

The Society recognizes that in managing a self-help group, volunteers may incur out-of-pocket expenditures.

Chapters have written policies that outline approved and unapproved expenditures incurred through the use of Society dollars. Approved expenditures are those that relate directly to the management and functioning of the group's operations and may include:

- Postage for mailed meeting reminders
- Meeting room rental costs
- Program presentation equipment such as projectors, video players or microphones
- Food, holiday parties and celebrations of the group's choosing
- Long distance phone calls to members or the chapter
- Purchase of small thank you gifts for meeting presenters
- Paying for transportation for the group members to attend a Society-sponsored event (e.g., hiring a van and driver to take members to the chapter's annual educational conference or state legislative day.)
  - Does not include transportation for attending group meetings. Some chapters have assistance available through other programs. See chapter liaison for further guidance.

While we do recognize that group members do care about the well-being of their fellow group members, there are some expenses that are not an appropriate use of Society funds. These include:

- “Sunshine” activities such as get well flowers or gifts for members (the purchase of get well or thank you cards is an acceptable use of Society funds). Group members can, if they wish, contribute their own monies towards these types of expenses.
- Financial assistance for MS-related needs\* (such as medications, home or auto modifications, etc.)
- Purchase or rental of durable medical equipment for group members (such as scooters, wheelchairs, canes, etc.). These types of requests should be made directly to the chapter or the Information Resource Center.)

## **1) Disbursement of Funds**

The ideal model for disbursement of funds to self-help groups is for the chapter to reimburse groups or individual members for approved expenses upon receipt of vouchers or receipts. Funds are disbursed by the group only in accordance with guidelines agreed upon by the chapter and group, and within the amount budgeted.

As an alternative, and only with pre-approval from the chapter management team, chapters may provide funds to groups to keep as a petty cash account or certain store gift cards, providing the group submits a ledger report showing all expenses under \$25. Receipts are to be submitted, along with the ledger report, only when a single expense exceeds \$25. If a chapter adopts this model, the monies kept in the petty cash account should be kept to an operational minimum (recommended amount is no more than \$250).

## **2) Self-Help Groups and Fundraising Activities**

There are occasions when self-help groups have the opportunity to or may choose to raise funds or seek underwriting for group related activities. The group should work with the chapter staff in advance of any fundraising initiative to ensure awareness of the proposed activity and secure prior approval.

The chapter staff and the self-help group leader(s) will discuss the benefits of the proposed activity and determine if the proposed activity conflicts with other chapter-sponsored events in the area or chapter relationships with sponsors or donors, etc. The staff might also be able to help the leader identify potential fundraising practices and opportunities. The decision on whether or not self-help groups can raise money through specific fundraising activities ultimately resides with the chapter management team.

If agreement is reached about a specific event or activity, the group must agree to raise funds in accordance with established chapter procedures. The chapter staff are responsible for sharing these procedures with the group leader.

For the chapter staff and the self-help group leader to come to agreement on a fundraising activity, and the chapter management team to approve, the following criteria must be met:

- The group has adequately addressed risk management issues (i.e., if the activity is held at a particular venue such as a community center, VFW hall, church basement, etc., the venue provides evidence of adequate insurance).
- The group has complied with any state laws governing the activity.
- The group leader works with the chapter staff to ensure any marketing materials developed for the fundraising activity are consistent with Society branding guidelines. The group representative and chapter staff will coordinate on chapter marketing/promotion opportunities at the event (such as banners, brochures, etc.).

### **3) Allowable Fundraising Activities and Funds Appropriations**

National MS Society self-help groups may, upon approval from the chapter, engage in low risk, small scale fundraising activities to raise funds to support the group's activities. These fundraising activities could include:

- Bake sales
- Yard sales
- Craft sales
- Car washes
- Auctions

Funds raised as part of these types of activities are exempt from the accepted policy that all funds raised must be submitted to the chapter, but only in those instances where there is no expectation by the donor of a tax-deductible donation. (See below for additional information on tax-deductible donations.) Self-help groups may maintain an operating fund of up to \$250, so funds raised up to \$250 may be kept by the group in a petty cash fund and used towards group expenses. It is recommended that groups do not accept checks for payment at these small scale events.

In those instances where groups can maintain a petty cash fund and the fundraising activity raises more than \$250 (or if funds raised put the petty cash fund over the \$250 limit) the amount over \$250 should be submitted to the chapter. In accordance with chapter policies, the chapter and the group will reach agreement on whether all or part of those funds over the \$250 petty cash threshold are earmarked for that group only, or are deposited to the larger self-help group or chapter operations funding pool.

Chapters of the National MS Society are exempt from income tax under section 501(c)3 of the Internal Revenue Service Code. This designation allows donors to deduct any contributions to chapters from their income tax return in accordance with current law. The 501(c)3 designation does not apply to self-help groups independently, so any monies collected by Society self-help groups, where donors have an expectation of a tax-deductible donation must be collected on behalf of, and submitted to, the chapter. This procedure allows the donor to take the tax deduction allowed by law. The chapter will then re-distribute the funds to the group or groups in accordance with chapter policies. In this case, any checks received should be made payable to the National MS Society.

If a donor requests that a contribution be restricted to a particular self-help group, this intent must be in writing and the funds must be directed to the chapter office where it is held as a restricted asset. The chapter will honor the intention of the donor; however, the chapter management team has the responsibility to decide whether or not it is possible to accept any restricted donation. Society policies preclude any staff person or volunteer from soliciting restricted gifts of less than \$500. This restriction is in place to ensure the chapter has the ability to direct operation funds to support the needs and priorities of the organization.

These small scale events managed by self-help groups provide an opportunity to educate the public about the Society. Prior to the fundraising activity the self-help group leader and chapter liaison should communicate and agree to the types of signage and chapter materials to have at the event. It is important to have signage at the event that clearly states that funds raised at this activity support 'ABC' Self-help Group of the 'DEF' Chapter, National MS Society and should also include the Society's logo. Chapter materials provided at the event could include chapter programs and services brochures, MS Navigator<sup>®</sup> brochures, Walk MS<sup>®</sup> or Bike MS<sup>®</sup> brochures, events calendars, etc.

#### **4) Do it Yourself Fundraising and Other Special Events**

Do It Yourself (DIY) Fundraising is an opportunity for people with a deep commitment to the MS cause to raise awareness and critical funds for the MS movement in new and creative ways. Activities can include golf tournaments, dinner parties, bake sales, endurance events, just asking your friends and more.

There may be times when a self-help group approaches chapter staff with a DIY fundraising idea. The guidance below should be followed if the idea is:

- Bigger in scope
- Has larger community appeal (e.g., a dance, comedy night, Scrabble tournament)
- AND has the potential to generate income over \$250.

In those instances, the chapter management team will determine if the chapter has the resources available to coordinate the event. If they do, the event falls under the category of ‘Other Special Events.’ Any monies raised from this event are to be deposited into the chapter’s general fund and could be restricted for the chapter’s overall self-help group program. These funds would not be restricted to the sole use of the group that generated the event idea.

If the chapter management team determines the chapter does not have the resources to coordinate the event, but does see value in the activity, the management team can work with the self-help group and have the group host the activity as a DIY fundraising activity. In order to qualify the event as a third-party event, the chapter must show that it is not involved in raising the money; that is—the event is entirely managed by the outside group.

Chapter staff are not involved in planning, income and expense accounting, or event execution and the chapter incurs no expense as a result of the event. Any monies raised from this event are to be deposited into the chapter’s general fund and could be restricted for the chapter’s overall self-help group program. These funds would not be restricted to the sole use of the group that generated the event idea. The Society has developed online fundraising tools, a special logo to be used for DIY fundraising activities and guidelines for the organizer. For more information please visit **[www.doityourselfms.org](http://www.doityourselfms.org)**.

At times, other organizations or interested persons may operate third-party fundraising events on behalf of the Society and choose to locally restrict the net income from those events (such as for a self-help group). It is important for the chapter management team to evaluate their restrictions prior to the event though to make sure the restrictions are appropriate and in alignment with the Society’s gift acceptance policies.

## **5) Unallowable Fundraising-related Activities**

- Due to state laws governing gaming activities, self-help groups are not allowed to raise funds through a raffle. Doors prizes are permissible, but groups cannot sell a chance to win.
- Other Dangerous Activities — if you are concerned that your DIY activity may be considered “dangerous” like skydiving, rock climbing, car racing, etc.; please contact your chapter liaison for a full list of unallowable fundraising-related activities.

- National MS Society self-help groups are prohibited from sponsoring fundraising activities that conflict with Society signature special events (Bike MS<sup>®</sup>, Walk MS<sup>®</sup>, Women on the Move luncheon, Dinner of Champions, etc.). Self-help groups are encouraged to have a Bike or Walk team, and in fact, many self-help groups are valued and highly successful fundraisers to the Society. However, money raised as part of the team cannot be restricted for the group's sole use.
- Self-help groups affiliated with the National MS Society cannot open any type of bank account in the name of the Society. Self-help groups may maintain a petty cash fund of up to \$250 to be used for expenses incurred by the group over the course of the year (see allowable expenses above).

## **I. Background Checks**

***Self-help group leaders complete a background check.***

Effective June 1, 2008, all Society Connection Program volunteers must complete a criminal background check as part of the application and screening process. Leaders who were trained and actively facilitating groups prior to this date are exempt. However, the Society reserves the right to conduct a screening on anyone for whom it becomes common knowledge of a questionable past history and to repeat background check every three years as needed.

If a group leader has a current background check for his/her job, a copy can be provided in lieu of a new background check, as long as it is a bona fide agency providing the check within the past year. If a married couple is leading a group, both parties must complete a background check.

## **J. Transportation for Members**

***Self-help group leaders do not provide transportation to group members.***

Self-help group leaders are not to transport group members to and from group meetings. Even though it is natural to want to help those who want to come and do not have a ride, leaders incur personal risk any time someone gets in their vehicles. Self-help group leaders put themselves and the Society at risk. In the event of an accident the driver's insurance is primary, so a well-meaning leader or group member could be held liable for any injury sustained by the passenger. The Society would also have secondary liability when the driver is a group leader. When transportation is an issue for a group member, leaders should recommend the member contact chapter staff to investigate community transit alternatives.



## **K. Liability Waivers**

### ***Self-help group leaders require liability waivers for some group activities.***

Some group activities may present the Society with a risk management problem due to the nature of the activity. Any exercise that is incorporated into the group meeting (including yoga) or that the group decides to go to together outside of a group meeting as a group requires a waiver that releases the Society of any liability should a group member get injured. Please get any activity pre-approved by your chapter liaison and ask for the appropriate waiver form if the activity is deemed acceptable by your liaison.

## **4. SELF-HELP GROUPS ARE FREE.**

If a self-help group asks members for contributions to defray minor expenses, these contributions shall not be mandatory. A group may, if members agree, have meetings in conjunction with a meal or activity in which members cover their own expenses. The chapter may offer to cover expenses of a lunch or recreational group for members who otherwise might not be able to attend, particularly in areas in which no alternative group is offered, however, there is no obligation to do so.

## **5. THE CHAPTER AND A SELF-HELP GROUP MAY DENY PARTICIPATION TO INDIVIDUALS WHOSE BEHAVIOR IS DISRUPTIVE TO THE GROUP PROCESS.**

The chapter and self-help group have the right to deny admittance to any person who persistently exhibits behaviors which are disruptive to group meetings, who harasses other members, or in other ways presents a risk to group members or to the meeting process. A disruptive group member can be extremely destructive in self-help groups, hurting both individuals and the group as a whole. It is also likely that this person may not be able to benefit from continued involvement in the group at this time and may need to be asked to leave the group. As hard as that is to do, one must consider the needs of the group as a whole against the needs of one disruptive person who appears unlikely to benefit from the group.

This difficult decision and subsequent plan of action should be developed jointly with the group leader, chapter staff and other parties who have an interest and responsibility in the matter. Chapter staff may seek appropriate alternative chapter programs or community services for the individual in question. A referral to an individual counselor may be more appropriate than a self-help group. You and your chapter liaison will need to decide who will ask the person to leave the group and offer the other resources (you as the leader, the chapter staff person, or an appropriate leadership volunteer). The request to leave should be made privately and should provide ample reasons for the decision. This situation doesn't happen often and it rarely feels like a good solution. Unfortunately, denying participation is sometimes the only way to deal with a disruptive member while keeping the group intact.

## **6. SELF-HELP GROUPS HAVE THE RIGHT TO CHOOSE DISCUSSION TOPICS AND SPEAKERS FOR MEETINGS AND HAVE THE RESPONSIBILITY TO MINIMIZE RISK TO GROUP MEMBERS AND TO THE CHAPTER.**

Chapter staff and program committee members develop the curriculum and agenda for nearly all chapter programs. Self-help groups are an exception, as the group participants plan meetings as well as choose speakers and discussion topics. In chapters with large numbers of groups, it is often impractical for staff to be aware of all of the information disseminated at group meetings.

Self-help group leaders have the responsibility to minimize risk to group members and to the chapter. Meeting agendas must not be in conflict with the Society's mission, policies or Code of Conduct. In accordance with the Code of Conduct, no staff person or volunteer may utilize a self-help group for personal gain. Chapter staff reinforce these policies by sharing the guidelines on working with for-profit organizations in leader trainings, and assisting groups to utilize these policies in making decisions about speakers and topics.

In the event that the agendas of a particular self-help group regularly and persistently demonstrate conflict with the mission and/or policies of the Society, and attempts at resolution have failed, the chapter has the option to dissolve the formal relationship with the group. This disassociation in no way affects the rights of individual group members to access other Society programs.

Self-help groups can minimize risk to themselves and the chapter through the use of the Self-Help Group Meeting Disclaimer. It is particularly appropriate for a meeting in which the topic focuses on medical information, treatment or therapy. Some groups post the disclaimer at each group meeting.

### **SELF-HELP GROUP MEETING DISCLAIMER**

The National MS Society respects the rights of people with MS to obtain any and all information they want related to MS including information on wellness, medical treatments or complementary therapies, products and services. The information presented at this meeting does not necessarily reflect the views or official position of the National Multiple Sclerosis Society, nor carry the endorsement or support of the Society. For specific medical advice, contact your physician. For the opinion of the National Medical Advisory Committee of the National MS Society on any therapy, treatment or product, please contact your chapter at 1-800-344-4867 (1-800-FIGHT-MS), or visit our Web site at [www.nationalMSSociety.org](http://www.nationalMSSociety.org).

## **7. CHAPTER STAFF AND SELF-HELP GROUPS SHARE RESPONSIBILITY TO ENSURE THAT GROUP AFFILIATIONS WITH OTHER ORGANIZATIONS ARE BENEFICIAL TO THE SOCIETY AND IN ACCORDANCE WITH NATIONAL MS SOCIETY POLICIES.**

Self-help groups are encouraged to utilize community resources through formal or informal affiliations, provided attention has been given to the focus and integrity of the other organization and the outcomes that will be achieved through the association.

Sometimes self-help groups are approached by other organizations, including other MS organizations, to form affiliations or working partnerships. When considering the pros and cons of affiliating with another organization, self-help group leaders and chapter staff collaborate to investigate the mission, reputation, credibility and activities of that organization. Before an affiliation is forged, both chapter staff and the group leaders need to be certain that there is no intent on the part of the other organization to exploit the Society or its members.

Affiliations are forged only when doing so will strengthen, not interfere with, the fulfillment of our mission. Other organizations may have different requirements and standards. Groups must adhere to those requirements and standards of the Society to have dual affiliation.

## **8. RELATIONSHIPS WITH PHARMACEUTICAL, MEDICAL DEVICE, RESEARCH OR OTHER COMPANIES ARE MANAGED THROUGH THE CHAPTER**

It is the responsibility of chapter staff to explain to their pharmaceutical representative that representatives are not to directly contact and support the chapter's self-help groups. Relationships with individual self-help groups are managed through the chapter. See Appendix B: Relationships with Pharmaceutical, Medical Device, Research or Other Companies: Frequently Asked Questions for further clarification.

## **9. SELF-HELP GROUPS ARE RESPECTFUL TO RELIGIOUS ISSUES**

Faith is an important coping mechanism for many people living with MS. However, the National MS Society is a secular organization, welcoming those of every faith and those who espouse none. In general, we ask that our groups do not include prayer as part of their formal meeting. By doing so the group runs the risk of alienating and/or excluding some group members, which is in direct conflict with the guideline pertaining to open membership.

Society policy does allow for groups to have a specific focus, as long as a more generic group is offered within reasonable proximity. If a group chooses to have a specific faith-oriented

focus, chapter staff must state that clearly in any promotional materials for the group and inform any potential members of the nature of the group.

For groups not specifically promoted as faith-based, prayer should not be incorporated into the actual agenda of the meeting. If members want to have a prayer component it should be an optional addendum to the meeting. Options would be:

- Invite group members to stay after the meeting for a prayer.
- Set a time before the start time of the meeting for a prayer.
- Have a moment of silence/time for personal contemplation/reflection at the start of the actual meeting.

## **GETTING STARTED**

The idea to start a new self-help group may be generated by the chapter or by an individual or group of individuals who would like to see a group offered in their area. Work closely with your chapter liaison to start your group. He/she will have ideas and resources to help you recruit members, find space, locate speakers, and will provide training and support to you and your co-leaders. It's much easier to start a group if the work is shared, so try to identify a "core group" of people who are willing to work together to start the group. If several people are involved in the initial work, they will also model for newcomers to the group what your group is all about—a group effort shared by many people working together. When many people are involved from the beginning, it will be easier to recruit volunteers later.

## **RECRUITING GROUP MEMBERS**

Before implementing any of the strategies below, talk to the chapter program director or other designated staff about your plan to recruit group members. The chapter may be able to place an item in their newsletter or do a targeted mailing of announcements to a particular geographic area. Also, be sure to run all written materials by the chapter before mailing or submitting for publication and/or distribution. This will ensure that information is consistent, accurate and complies with the Society's Self-Help Group Standards.

- Place notices in key posting areas: churches, schools, organizations, clubs, shops, hospitals, nursing homes, community bulletin boards, libraries, post offices, etc.
- Print and distribute a flyer or business card describing your group. (Your chapter liaison can access a Society business card template designed for self-help group leaders.)

- Speak to clergy, doctors, administrators, agency directors, social workers, media personnel and nurses (i.e., anyone who might be willing to spread the word).
- Discover and connect with social media contacts in the area.
- Contact your local hospital social services department, community health education department, neurologists and other doctors who treat people with MS.
- Talk to other leaders who have started Society self-help groups and ask what methods they used to recruit group members.
- Talk to public relations staff at local industries/businesses about getting ads in their periodicals or newsletters.
- Call your local information and referral helpline/hotlines—make sure they know of your group’s existence.
- Determine which agency/organizations print community or social service directories, contact them and request your group be included.
- Write a brief notice and ask that it be placed in the church bulletin/newsletter or other community newsletters.
- Write a brief radio spot and send it to local radio stations requesting they air it as a public service announcement.
- Advertise the group on local/cable TV.

*Adapted from: “Suggested Techniques for Recruiting Group Members”; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

### **Handling Group Contact Telephone Calls**

As a contact person, you serve as the essential link between someone in need, your self-help group and your chapter.

After you and your chapter publicize your group, you (or a designated group member) may begin receiving telephone calls from people who are interested in your group. As a contact person, you serve as the essential link between someone in need, your self-help group, and your chapter. When a prospective member finally gets the courage to call, your response can determine whether or not that person will come to a meeting. You are also a crucial link to the public at large; your phone number and name probably appear on your group’s flyers and media announcements and/or in the chapter’s newsletter. Your responsibilities can sometimes seem overwhelming unless you have some support and can share the load.

### **Tips for Successful Contact Calls**

Note the courage of the caller. As a self-help group contact person you are often the first person the caller has reached out to and asked for help. Many people find it exceedingly difficult to admit they need help dealing with their MS. To go one step further and ask a stranger for help is clearly a courageous act. To support a caller, who may be extremely anxious during this initial contact:

- Compliment the person on having called.
- Be an active listener. Don't interrupt with your story or advice.
- Clarify the person's problem or need. During the course of the conversation clarify the caller's issues and expectations. If your group is not likely to meet the caller's expectations, let the person know and, if possible, refer him/her to a more appropriate resource.
- Share some of your experience. While sharing experiences is fundamental to self-help, during this initial contact talk about your own MS only as it relates to the caller's experiences. Refrain from overwhelming callers with the burden of your issues as well as his/her own.
- Be clear about your limitations. Rather than present yourself as an "authority" on MS or a therapist, be yourself—another person who lives with MS—and focus on sharing what has worked for you. Refer callers to the chapter for information and referrals.
- Follow through on promises. The credibility of your group is at stake. If you make any promises, (e.g. returning the call, sending literature, etc.) follow through as soon as possible. If you do not have the time, ask for some assistance from other group members.
- Be as accurate as possible. As a contact person, you need to explain the purpose of your group and what it does and does not offer. Although you may be very enthusiastic about your group, too much enthusiasm during this initial contact, particularly regarding your group's philosophy or beliefs, can turn people away. Beware of overwhelming your caller.
- Offer the Facts: Callers will need the date, time and meeting place of your group.

Since people often get nervous at the prospect of attending a meeting with a group of strangers, your job as contact person is to lessen some of that anxiety to make it possible for them to take that next step. Some useful strategies include:

- Acknowledging the caller's concerns. Letting a person know that most people feel nervous about coming to a first meeting can be reassuring to a caller. Offer to meet prospective members at the door a few minutes before the meeting begins to help them get acquainted. Just knowing that a somewhat familiar person will greet him or her can help a person feel more comfortable.

- Describing a typical group meeting. People tend to be more willing to approach new situations if they know what to expect. In describing a typical meeting, include general information and a description of how a meeting works. Reassure the caller that the group respects a person's decision to not participate in group discussions. This is particularly important for people who are anxious about talking in front of groups.
- Respecting a caller's decision to not attend a meeting. Let callers decide if and when they are ready to come to a meeting and respect that decision. People who are initially hesitant sometimes need to give their situation a little more thought before they're ready to take that next step.
- Setting limits on your availability to listen. Since a group helps in ways that extend far beyond a phone call, keep in mind that your job is to help people take their next step toward helping themselves—joining a self-help group. If the caller gets all of his/her needs met on the phone, he/she may not come to any meetings. A useful technique for this situation is to let the caller know that you think what they are saying is important, so important that it should be saved for the whole group to hear.
- Getting calls at inconvenient times. If you do not use an answering machine, you may be plagued by inquiries at times when you are least able to focus attention on the caller. One way of dealing with this situation is to gently say, "I only have a few minutes to talk right now. I'd be happy to call you back at a later time." If the caller is upset, refer them to your back-up contact person.
- A person in crisis. For most contact people the most difficult caller you may encounter is a person who is suicidal or experiencing an emotional crisis. The call is difficult for a number of reasons, not the least of which is the contact person's concern for "doing the right thing." Keep in mind that as a contact person, it is not your job to provide crisis intervention. Your major goal is to try to calm the caller down so that you can refer them to an appropriate resource or collect enough information (i.e., name and location) to get a local emergency team to the caller. Always contact the chapter if you have had to deal with a crisis call. (See the section "Handling a Crisis Situation" for further suggestions on handling crisis situations.)
- Referring callers to other resources. As noted above, it is vital to have a list of local resources near the phone when dealing with someone in crisis. Refer calls to an MS Navigator at 1-800-344-4867 for further resources.
- Dealing with the media. Refer calls from radio, TV and newspapers to the chapter, unless they are calling to clarify your meeting times and dates.

Sometimes being a group contact person can feel like it is taking all of your time and energy. Burnout is a serious problem with no easy solutions. However, you can work to organize your group so that no one is unduly stressed. Suggested strategies to prevent burnout include:

- Have more than one contact person and rotate the name of the first person listed on any publicity material. This will provide a more even distribution of calls among your contact people with no one serving as the “one and only.”
- Limit the contact person’s length of service. If your group receives many phone calls, it can help to know that you will be rotated off duty after a certain amount of time. Just anticipating the “foreverness” of the duty can accelerate burnout.
- Share with your group. As a final point, please keep in sight the fact that you are a member of a support group . . . people helping people. If you feel overburdened, or if you are concerned about a particular call, share your feelings with the other members of your group. That’s what it’s all about.

*Adapted from: “Some Help for the Helper: A Guide for the Self-Help Group Contact Person” by Barbara White and Pat de la Fuente; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

### **Handling Group Email Contact**

Most groups find email to be the quickest and most efficient way of keeping connected. However, there are a few email protocols that should be considered before using email as your primary method of communication.

- Confidentiality: The majority of people are comfortable with communicating by way of email. Be cautious when sending group emails and use the Blind Carbon Copy (Bcc) method to protect their privacy. If individuals are comfortable with their email address being shared, ask them to make that known to the group. You are strongly encouraged to use **msconnection.org** for any between meeting conversations between group members. For more information check out the Resources and Support for connection program volunteers page for a recorded telelearning on setting up an online group: <http://www.nationalmssociety.org/living-with-multiple-sclerosis/connection-programs/resources-and-support-for-self-help-group-leaders/index.aspx>
- More on Blind Carbon Copies: Be sure to note in the body of the email to whom it is being sent. For Example: This email has been blind carbon copied to all But You Look So Good Self-Help Group Members.
- E-Mail Text & Subject: When sending an email be courteous and keep your message brief and to the point of the subject. If necessary send two or three emails on different subjects to avoid loading one message down with numerous topics. Or you



may opt to make the subject title “Update” which allows you to summarize several topics as long as the summary is brief.

- **Font and Text Size:** In order to make your messages as clear as possible use Text Size 14. You should not use a font that appears in cursive or script.
- **Random Email Forwarding:** As a Leader your emails should pertain to your meetings or multiple sclerosis. Avoid using your role to send out random subject emails on various topics to the group. Certainly if you have a friend that you communicate with that happens to be part of the group – then send those emails only to those that you know share that interest.
- **Replies:** Use “Reply to All” only when the reply made is germane to the whole group. If it only pertains to 1 or 2 members, then just send it to those. Remember over 3 emails on the same subject is actually a conversation. Pick up the phone or continue the conversation in person.
- **Emails STAY in Cyberspace:** Be cautious what you say in an email and avoid sensitive and certainly confidential topics. It is best to keep sensitive subjects to a time when you can communicate in private either in person or over the phone.
- **Ask before you send attachments.** Compress all attachments to a PDF format and reduce the size of pictures. Sending mega emails can choke an individual’s in-box and may prevent a user from receiving their emails
- **Let people know their email has been received:** As a leader you will be receiving emails from the public and your group members. When receiving an inquiry please let the person know it has been received. If you cannot adequately answer at that moment, offer a time frame for when it will be addressed. In the event you feel unsure of your response, reply to the individual that you will get back to them and give an approximate day. Feel free to forward the email to your National MS Society chapter liaison for assistance.
- **Writing in All Caps is like SHOUTING!** When composing e-mail messages, it is important to send the right tone. Avoid using all caps in your emails. Keep messages short and professional.
- **Review Before Sending:** Review your messages before you press the send button. This practice helps you to prevent the need to send repeated corrections on what you meant to convey.

## **LOCATING MEETING SPACE**

A key standard for all National MS Society programs is that meetings are held in a fully accessible location. This should be your number one priority in looking for meeting space for your group. Your chapter can give you a copy of the accessibility checklist to assist you in evaluating the accessibility of a particular location.

In addition to full accessibility, try to find space that:

- Is conveniently located and easy to find
- Has plenty of parking
- Is well-lit and safe
- Is air-conditioned/appropriately heated
- Is clean
- Is cheerful and welcoming
- Has comfortable seating
- Has a flexible room set-up
- Has a kitchen or place to serve refreshments
- Has a public telephone available
- Has liability insurance
- Has wi-fi and DVD player/equipment available

Here are some helpful suggestions for locating a meeting space:

- Private homes are not acceptable meeting locations because most homes do not meet the accessibility requirements of the Americans with Disabilities Act. In addition, the homeowner and his or her insurance company will be responsible for any injuries that occur in the home.
- Ask your chapter to recommend accessible sites in your area. They can also provide accessibility expertise and can help you negotiate with facilities if necessary.
- Places of worship are a common public meeting place for self-help groups. They are usually cooperative in providing space. You and members of your core group can contact your pastor or rabbi and request a room for your meeting. The personal connection is the best and could mean no charge initially, or a minimal charge or donation.
- Community organizations or agencies such as community mental health centers, Red Cross, Salvation Army, Rotary, Lions, Kiwanis Clubs, or senior citizens centers will sometimes provide space free of charge for self-help group meetings. Again, does anyone in your group personally know a staff member or officer? Your local library or daycare centers and schools, banks, municipal town hall or community college are other facilities where self-help groups hold meetings.
- Hospitals or other healthcare facilities are another option. Contact the community relations department or the social services department to request a meeting place.
- Your local YMCA/YWCA also may provide meeting space for self-help groups. Contact the community relations staff person at the “Y”.

- When inquiring about a meeting place for your group, be sure to communicate that your group is affiliated with a voluntary non-profit organization that provides a service to the public free of charge. Be clear on the specific nights/days that you would like your meetings to take place, how long they will be and who will be responsible for opening and closing the facility. Such attention to detail will serve you and your group well!

*Adapted from: "Suggestions for Locating a Meeting Space"; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## **TIPS FOR YOUR FIRST MEETING**

At the first meeting, describe to members the relationship between the chapter and the group. Underscore the fact that the group is a self-help group that is affiliated with the \_\_\_\_\_ Chapter of the National MS Society. Invite your chapter liaison to attend the first meeting and perhaps say a few words about the Society and the chapter.

Here are some additional tips for the first meeting:

- Before your first public meeting, be sure the leadership group has had an opportunity to discuss, and reach a consensus on, what the general purpose, goals, and membership of the group might be so they may present those ideas at this meeting.
- Create a friendly atmosphere from the beginning. Consider having a member of your core group to serve as a greeter to welcome and introduce newcomers when they arrive.
- At the first meeting, the group leader(s) should state the group's possible purpose and goals to the new members for their comments and feedback. Review the Society's Self-Help Group Standards. Stress the importance of complying with these standards. They serve to create a welcoming and safe environment, as well as strengthen the group's relationship to the Society. Also, the group leader(s) can take the opportunity to share their experiences that led to their interest in the formation of the group. This can encourage others to share their own experiences.
- Be sure new members are given an opportunity to introduce themselves and briefly tell their "personal story" if they wish. Do not pressure them to tell all at the first meeting. It may take several meetings before some people feel comfortable enough to participate and share openly. Also, don't require nametags or introductions that require the individual to reveal personal information. Allow members to remain anonymous if they choose.
- Discussing a name for the group is an interesting agenda item. A name provides an identity and uniqueness for the group. Allowing the members to suggest a name for the group can be an interesting activity for this first meeting (e.g. an appropriate phrase, acronym, etc.).

- Dealing with organizational issues such as elections of leaders may be too burdensome for the first meeting and might be more easily taken up at subsequent meetings.
- Start and finish your meeting on time. Have an agenda and activities or discussion questions prepared that you intend to follow. Be flexible, however, and allow members to speak freely. The group leader(s) can always ask the group if they want to extend the time of the meeting.
- Refreshments may be provided before and/or after the meeting. This provides an informal atmosphere and allows members to more easily socialize, discuss problems, get to know one another and contribute to the group if members share the responsibility. Some groups may choose not to provide refreshments.
- There are different models of structure and leadership used by groups ranging from highly organized groups with elected officers, to loosely structured groups using an informal shared leadership model. Whatever style of leadership your group chooses, remember, the purpose of leadership in a National MS Society self-help group is to initiate and facilitate the mutual aid process that occurs when members share their own insights and skills in living with MS.
- Before adjourning the meeting, decide on the time and place of your next meeting or announce this information if it is already determined.

*Adapted from: "Helpful Hints for a Successful First Meeting"; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## **KEEPING UP THE MOMENTUM**

After the first meeting, it is important to keep up the momentum and energy generated. Here are some tips to do so:

- Encourage networking. Introduce a new member to a group member with similar symptoms and suggest they talk. Greeters at group meetings can do this task.
- Try a buddy system. A new member is matched with another group member who can partner with that person and assist him or her as needed. It can be time-limited.
- Establish a telephone tree. This technique is often used to alert members to a pressing, time-sensitive or action-needed issue (e.g. legislative alert or to cancel meetings because of bad weather). It requires a coordinator and volunteers. When needed, the telephone tree coordinator phones the telephone tree volunteers with the information. Each volunteer has a pre-assigned section of the list of members' phone numbers. Be sure to obtain permission to list members' names and phone numbers on the tree.
- Establish a correspondence network. Interested members join an online group on the **MSconnection.org** community to stay in touch between meetings.

- Send a meeting reminder and/or keep your chapter informed about your group's schedule and topics so it can be included in the chapter newsletter.
- Engage in advocacy activities. Members work together for legal or social change or to reform specific government or agency procedures. They can do this in different ways (e.g. demonstrations, letter writing, speaking at hearings, developing and distributing flyers, participating in a coalition, or by working on advisory councils or boards). Work with the chapter to find out how you can be an advocate.
- Plan social activities: This can include potlucks, holiday parties, picnics, or going out for entertainment together.

*Adapted from: "Ways that Self-Help Groups Provide Mutual Support Between Meetings"; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## **BUILDING SHARED LEADERSHIP**

Think shared leadership and understand mutual responsibility from the outset.

In a self-help group, the role of facilitation, leadership of group discussion and ongoing management of the group is not the sole responsibility of one person but is the duty of the entire group. Members of self-help groups that use a shared leadership model of organization will find themselves involved in determining the direction of the group. Members will develop a strong sense of ownership in the group when they help plan discussion topics that help them adjust to having MS in their lives, recruit speakers that help them manage MS, publicize the group, take turns facilitating group discussions and help manage the group process.

To create shared leadership, all members must be aware of their obligations. Perhaps one way to accomplish this is to create a verbal (or written) agreement with all members. By creating an agreement among members, ownership of the group is shared and group responsibility among members is clearly understood. This agreement could include the following:

- Help members feel comfortable and become acquainted.
- Listen attentively when another member is speaking and discourage side conversations.
- Promote positive comments and new viewpoints, trying to keep the conversation upbeat.
- Notice silent people in the group and gently encourage them to contribute; however, participants should not feel pressured to contribute.
- Participate in the discussion.
- Suggest alternate resources when a member's problem is beyond the group's ability to help.

- Allow members to express negative or angry feelings, but do not allow the group to dwell in negativity.
- Maintain confidentiality within the group to promote honest expression.
- Make a commitment to the group, contributing whatever talents, skills, resources, or information necessary to ensure the group's success and survival.

*Adapted from: "Responsibility of Group Members to Each Other"; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## **How to Build Shared Leadership**

Here are some suggestions to consider for distributing the sense of ownership and responsibility for leadership throughout the whole group, easing the burden on any one individual and ensuring both openness and continuity for the group:

- Think shared leadership from the outset. While the group is still in its earliest stages of formation, set the precedent of sharing tasks and resources so that, at the very least, there are two people taking responsibility for what has to get done and no one person does it all. In the short run it may seem easier to do things completely by yourself, but such a pattern is very easily set and quite hard to break; you become the expert, and the "best person to do it", at the cost of mutual aid and shared ownership. In addition, since multiple sclerosis is a variable and unpredictable disease, co-leadership creates a natural back-up system.
- Rotate leadership and other tasks. Once the group is up and meeting, change, in a planned way (i.e. weekly, monthly, quarterly, or annually), the person who runs the meetings, arranges speakers, sets up refreshments, etc.
- For example, a co-leader can help the leader during the first week or two of the designated period, and then take primary responsibility "breaking in" the next co-leader at the same time. This strategy is applicable to many tasks and functions, and in addition to promoting a nice flow of participation among the group, over time it can engender a sense of continuity.
- Vary meeting times occasionally. While regularity of time (and place) is obviously helpful in developing group stability, there are some people who may systematically be excluded from attendance if the group only meets, for example, on Tuesday evenings or the third Wednesday of every month. Therefore, it may be a good idea to have at least the first few meetings at different times during the week, so that many interested people can have a chance to attend.
- Adjust seating arrangements to facilitate sharing, while allowing room for people using wheelchairs or scooters. When the seating is arranged with people in rows facing the front of a room, facing group leaders, the group's tendency is to deal only through the leader(s), rather than through a mutual exchange process. Less

dependence on a leader will develop when all group members face each other in a circle or around a table.

- Integrate new group members by using inviting words and actions. In addition to verbally welcoming new people to the group, try to be aware of how the group experience seems by a newcomer and seat yourselves accordingly; distribute old-timers among the newer or less-known group members.
- Similarly, share the history and knowledge of the group by making available to newcomers prior meeting minutes or summaries, and if appropriate, current members' names and telephone numbers. Call the newcomer sometime after the meeting to follow up and review their experience. These strategies can help ease feelings of “newness” and further increase a sense of belonging.

Broaden the base of active group members while identifying and preparing future leaders. If one thinks of leadership as occupying one end of a continuum, the other end of which is non-involvement and ultimately non-attendance, then a general strategy of shared leadership moves people toward the high-involvement end of the continuum. Several ways to do this are:

- Based on comments made in the meetings, quietly and perhaps outside of the group, ask individuals to help you or other leaders with specific tasks and projects you suspect they might find interesting. This gives them experience without too much responsibility and links people who may not know each other.
- Build on already existing friendships in the group by asking pairs or trios of people to take on projects together.
- Publicly acknowledge and express appreciation for work done by others; this not only pleases people (usually), but also helps others to realize just how much work is getting done.
- Tell stories and elicit stories about how a particular task was accomplished and, when appropriate, relate your own mistakes and lessons learned—this de-mystifies both tasks and leadership and making each more feasible for your members.
- Have fun and enjoy the group. People want to be involved in endeavors that are upbeat and make them feel good.
- Make room for others by being sensitive to people's messages and signals; know when to step back and let others do the work. Be available for advice and support, but let others work!

*Adapted from: “How to Build Shared Leadership”; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

Here are some additional ways to share responsibilities:

- Identify and name the jobs that need to be done. Consider “brainstorming” at one of your meetings. Come up with a list of the jobs and be as clear as possible as to what will be involved. Circulate a Sign-up Sheet at meetings (see example, or create a chart that meets your need).
- Ask potential volunteers one-on-one in private. Be sure to indicate how you will support them if they need assistance.
- Ask members to serve in a specific job but allow them to volunteer for something else.
- Always specify how long the volunteer will be expected to serve (e.g. 3 months, 6 months). Consider a fixed term of office for some jobs (e.g. 1 year, 2 years).
- Nurture and grow volunteers. Find small helper jobs (e.g. hand out brochures, do photocopying) and be sure to thank them. They might be willing to try a more difficult task next time.
- If you encounter problems in finding one individual to do a specific job, ask for two people to volunteer to share the responsibility of that job. More people will accept if they know it won’t be all on their shoulders.
- Be sure to continuously acknowledge people publicly for the jobs/tasks accomplished. This can be done through newsletters, as well as at meetings.
- Circulate or hand out Skills/Resources Sheets. Every member fills out a sheet with their name and skills description, type of personal contacts and phone number. (e.g. journalist in the family, uncle is a caterer, etc.). Eventually you will have a list of names, skills and resources to match up with your jobs. It may be a helpful list to check for a fill-in person if someone suddenly leaves or resigns from the group. The skills category may provide new and exciting positions; for example, if someone just writes “give great parties,” sign them up as the holiday party chairperson!

Name	Skills	Helpful Contacts	Phone Number	Email Address
J. Doe	Graphic Design	Friend is a printer	555-555-5555	hello@shgl.com
M. Smith	Marketing	Sister works at the local newspaper	555-555-5555	marketer@shgl.com



The Responsibility Sign-up Sheet shows examples of some jobs, duties, times, and terms. Revise or add to them as you see fit in order to meet your group's specific needs.

### RESPONSIBILITY SIGN-UP SHEET

Responsibility	Description	Hours/ month	Term Length	Volunteer
Speaker liaison	Contact and arrange for guest speakers as decided upon by members; thank speakers after the meeting.	4-5 hours	3-6 months	
Marketing/ Publicity	Work with chapter and local media outlets on marketing the group (press releases, PSAs, etc.).	4-5	6 months	
Hospitality	Arrange for refreshments at meetings.	2-3	6 months	
Greeter	Welcome new members; introduce them to other members—especially those with similar experiences.	1-4	3-6 months	
Contact	Point of contact for people interested in attending the group; provide information related to meeting time, location, focus of the group, etc.	4-10	6 months	

*Sign-up sheet adapted from: "Sharing the Load: A Few Ideas for Recruiting Members for Group Tasks"; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## MANAGING THE MEETING

### Rules for Group Discussion

No matter how informal your group, there are unspoken rules of communication. Your group may want to define what you consider to be acceptable behavior in the group. In addition, rules help everyone take responsibility for the success of your group.

Rules are best when used to liberate your group and make your meetings effective. Guidelines help to identify productive and unproductive behavior. Therefore, a person's behavior, not the person, is the target of correction. A few specific examples follow. Many groups read their guidelines at the beginning of each meeting to help set the tone for the meeting, to introduce the guidelines to new members to the group and to remind members of expected behavior.

- The order in which people speak and the amount of time each person is permitted to speak can be predetermined. No one should monopolize the group and everyone who wants to speak should have the opportunity. "Round Robin" means people take their turn to speak in seating order. "Random" means that people speak when they want to, allowing everyone a chance to speak.
- Some groups have an outline for people to follow when they first speak. The following combines several outlines: Your first name; what brought you to the group; rate your week on a scale of 1–10; tell about one good thing that happened over the past week (which helps set an optimistic tone); how you are feeling right now; and one positive thing that you would like to do over the next week.
- An "outline" for participation helps keep people on track when they speak. The format can also include using a predetermined question or topic meant to trigger discussion or a predetermined person may tell his/her story. People can either respond to the topic of the meeting or not when they take their turn to speak. Response to the subject should always be voluntary.
- Treat all members with respect. Establishing respectful behavior in your group creates an environment of trust and safety. Respectful behavior includes allowing one person at a time to speak, using appropriate language and tone of voice, accepting differences and treating each other with kindness.
- Most groups today request that each person use "I statements" when speaking during a meeting. This means that people always speak in the first person about their own experience. "I statements" are a way of enacting a "withhold judgment" rule. For example, a participant may say, "I am sad about . . .," "I feel very angry because. . .," or "I felt happy when. . ."
- The following examples are not "I" statements and usually are not helpful: "You should . . .," "You ought to . . .," "You are . . .," and "I think you are being. . ." You

may offer your own experience and what worked for you in solving a problem, but do not give advice as to what someone else should do.

- Withhold judgments. Many groups expressly prohibit making judgments. It is easy for all of us to make judgments without realizing it and with the best of intentions. No judgment means do not use the words “should” or “ought”. No judgment also means no advice, criticisms, accusations, or attacks, especially when discussing MS treatments or doctors. Whether written or not this rule is basic for all group participants to feel supported.
- Problem-solving only with permission. When someone raises a personal problem, avoid premature problem solving. The person will not feel heard and there may be circumstances that you do not fully understand. The group can be a valuable and enriching resource for problem-solving, but only when the person with the problem asks for this kind of help and is ready to hear it. Many times people just want to ventilate their frustrations, fears or anger.
- Respect other members’ perspectives/perceptions. There should be no second guessing, i.e., if a speaker says she is angry, it is inappropriate to respond with, “You don’t look angry.” “If you are angry, why are you smiling?” or “I wasn’t angry when that happened to me.” In other words, it is important that people feel that they are being listened to, respected and heard. If group members are unsure what another member is saying they may want to restate what the speaker has said. This is to ensure what is being heard is what is being said.
- One person at a time speaks. This means no side conversations or interruptions. Attention is focused on the person speaking.
- Use caution when discussing potential “hot topic” issues such as politics and religion. Your group may decide that it doesn’t want to discuss issues that have the potential to damage the group.
- Allow silences. Everyone has the right to listen silently. If you are concerned that someone is silent because their needs are not being met, you may approach them after a meeting to check this out.
- Punctuality. In order to start and end on time, most groups must make punctuality a conscious effort or rule. Many people believe it is a show of respect to arrive on time and to begin the meeting on time. It is helpful to many people to adhere to a predictable schedule for the beginning and ending of meetings. Informal socializing and networking can take place before and after the meeting. Whether your group wants to be casual or structured about time, make it a conscious group decision. Make punctuality a conscious effort.

Your group can decide how to maximize its effectiveness. A group is most effective when the atmosphere, communication style and attitude of those attending are positive, encouraging and respectful. People should be welcoming and feel welcomed. One of the most beneficial aspects of a self-help group is when people can speak candidly about their feelings and thoughts about MS and still experience acceptance. For some people a self-help group is the only place where this happens in their life.

Some rules may seem awkward at first but think about the kind of group that you want for yourself and for others. Each group consciously or unconsciously develops its own “culture” which usually differs from most social situations in the “outside” world. That is why it is a valuable place, sometimes a haven, for group participants. Bear in mind that no one person is more important than the group in any discussion about group rules.

### **Establishing Group Rules/Guidelines**

National Multiple Sclerosis Society self-help groups follow the standards outlined at the beginning of this manual. Those standards address the global behaviors expected of self-help group leaders and members (like confidentiality and fiscal responsibility), but your group may find it needs specific guidelines to help it function efficiently. Group rules work best when all the group members agree on the rules, members are reminded of the rules, new members are informed of the rules and the rules are reviewed and revised as necessary.

- Set aside at least one hour during a group meeting to discuss establishing rules. (This only needs to be done initially and re-visited when necessary to reinforce or modify the rules or inform new members.)
- Explain the benefits of group rules and give some examples of how they may have helped resolve a problem.
- Ask members to list possible group rules (don’t rule any of them out at this point).
- Discuss each possible rule and determine by consensus (everyone agrees) whether or not the rule will be beneficial to your group.
- Review the remaining rules and determine by consensus if these are the rules your group would like to adopt. If not, repeat step 4 and then step 5 until members reach consensus.
- Agree on a trial period to try out the rules and then schedule a meeting to review and revise the rules.
- Read (or post) the rules at each meeting.
- Review the rules annually.

## **Ways to Keep Your Meetings Upbeat**

Here are some ideas to help your group members focus on sharing positive experiences, insights, and information—and avoid the risk of having a “pity party” meeting that has people going home feeling worse than before they came.

- Read your meeting guidelines at the start of each meeting. One of those guidelines should explain that an important purpose of your group meetings is to help all members to recognize and share their strengths, successes and hopes, not just their problems.
- Help your members share their good experiences by reminding them to contribute their insights, quotes, information on helpful resources or literature they have used, or any practical coping techniques that work for them. For example, you could build this into the structure of your meetings by regularly starting your meetings with introductions and brief “go-round” that permits each member to briefly answer a question that draws out a positive experience (e.g. “Describe the best things that you’ve done [or have happened to you] since the last meeting [or over the last month].” Or a similar question could be developed that helps people to share their successes, joys, for what they are thankful, etc.).
- Share good news gathered from outside the group related to multiple sclerosis (e.g. new research results, helpful magazine articles, news from other organizations and agencies that address disability issues, etc.).
- Make members more aware of the real health benefits of helping others. “One of the best ways to take your mind off your own issues is to help others with theirs” (i.e. helping members to recognize how helpful it is to give other members feedback, whether it be to summarize the progress of others and the group or to give a helpful “nod of understanding” when a member is sharing).

*Adapted from: “Ya Gotta Accentuate the Positive . . . Ways to Keep Your Self-Help Group Meetings Upbeat”; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## **Ways to Structure Your Group Meetings**

Meeting formats for National MS Society self-help groups range from loosely structured discussion groups to more formally structured meetings. The following activities are common to many self-help group meetings and can be used as a guide for structuring your meeting. It is not necessary to incorporate every activity mentioned here in each meeting agenda.

- Greeting of new members. It is a practice of many self-help groups that a volunteer member greets and welcomes new members at the door when they arrive, introducing them to other members.

- Formal opening of meeting. At the agreed upon time, the meeting should be called to order by the leader or member responsible for the meeting. Some groups open their meetings with a formal statement of the group's purpose or welcoming statements.
- Introduction of members. Going around the room, each member can introduce himself/herself and may state their reasons for coming to the group. This is especially appropriate for new groups forming to help members get to know one another and learn about common concerns. Offer members the option to "pass" if they would rather not introduce themselves.
- Discussion, education, and information sharing. For newly formed groups, it is helpful to regularly ask members for suggestions on discussion topics that are of interest to them. Groups can also invite guest speakers to address topics. Audio recordings, books or articles can be reviewed and discussed. Time is allotted for sharing of personal experiences and helping each other. Here are some ways to structure the discussion.
- Round. Ask a question or ask participants to complete a statement and go around the group as each person responds, giving everyone a chance.
- Brainstorming. Ideas are shared in a spontaneous way. Creative thinking is encouraged by not judging any particular idea.
- Change exercise. Describe a current situation, describe what you want it to be in the future, list the things that hold you back, things that could help you move forward, what would be affected by the change and the steps needed to bring about the change. This can be used to discuss an individual's personal dilemma or a generic situation.
- Role-playing. Acting out a situation (e.g. how to communicate effectively with your doctor) can be helpful and fun. Some participants enact the role-play while others observe and can react or comment.
- Business section. This time is set aside for any business the group wishes to take up, such as planning projects or activities, arranging for future meetings (choosing discussion topics/guest speakers, etc.), making announcements, etc.
- Formal closing. It is important that some signal be given to indicate that the meeting is formally closed. Members are reminded of time and place of next meeting.
- Refreshments. Serving refreshments after the meetings provides a time for informal meeting and conversation.

*Adapted from: "Suggestions for Structuring a Self-Help Group Meeting"; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## **GUEST SPEAKERS, MEETING IDEAS, TOPICS, AND DISCUSSION QUESTIONS**

As you plan topics, speakers and meeting ideas you should begin on the Connection Program Volunteer Resources and Support page at:

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/connection-programs/resources-and-support-for-self-help-group-leaders/index.aspx>

### **Finding Guest Speakers**

National MS Society self-help groups are an excellent source of information about multiple sclerosis. Self-help group members receive accurate information about the disease by sharing tools and tips about living with the disease, utilizing National MS Society information and literature and engaging a variety of speakers.

Follow Society self-help group standards regarding minimizing risk to group members and the chapter when selecting speakers and program topics. Use the Self-Help Group Disclaimer (see Standard #6) and make every effort to offer unbiased, well-rounded programs. Your chapter liaison will have many ideas for potential speakers and group programs and will know if a presenter you are considering has worked with the National MS Society previously and if the speaker meets the Society's Guidelines for Working with For-Profits.

Professional speaker suggestions:

- Neurologists
- Psychiatrists
- Urologists
- Nurses
- Physical therapists
- Occupational therapists
- Speech therapists
- Licensed clinical social workers
- Recreational therapists
- Music therapists
- Exercise therapists
- Tap the experience and contacts of your group members because a member's personal knowledge of a speaker is usually a good reference. Also, a potential speaker may be more likely to respond to someone he or she knows personally. Does someone in your group know of a local professional (e.g. a physician, therapist or lawyer) who is knowledgeable and can be approached?

- Local social service and government agencies and hospitals—sometimes they already have lists/brochures of possible speakers; contact the public/community relations department. If you know what you want, start at the top by writing a letter to the Director or C.E.O.
- Local colleges and universities—write/call the chairperson of a specific department related to your group’s interest. For example, contact the Psychology Department for speakers to address stress, the Nursing Department for self-care instruction, etc.
- Contact government agencies—Social Security Administration, Division of Vocational Rehabilitation, etc.
- Lawyers—especially those specializing in discrimination law, financial planning, insurance and disability law.
- Professional associations (of psychologists, social workers, nurses, doctors, county medical society and others)—for local speakers on subjects such as stress management, a specific type of therapy, medications, choosing a good therapist/doctor, etc.
- Alternative health providers—on herbal medicine, meditation, yoga or another. Be sure to follow Society’s Self-Help Group Guidelines regarding minimizing risk to group members when exploring this option (Standard #6). Do not have an alternative practitioner demonstrate on a group member (e.g. having a bee sting, a chiropractic manipulation, etc.).
- Local pharmacist—on drug interactions and taking medicines wisely.
- Representatives from another Society self-help group —to speak about their group’s best meetings, discussions, speakers and other successful activities they have had.
- Consider using a pre-recorded or “canned” speaker (e.g. recording of a radio interview show (25 minutes long or less), conference presentation, portion of a TV program, etc.). Or start an audio library of your own, by asking some of your “live” guests if you may record their presentation for your group’s lending library collection.
- When wireless internet and audio equipment available consider using video and/or materials from MS Learn Online and Resources and Support page for Connection Program Volunteers. <http://www.nationalmssociety.org/living-with-multiple-sclerosis/connection-programs/resources-and-support-for-self-help-group-leaders/index.aspx>

*Adapted from: “Finding Guest Speakers for Your Group”; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*



## **Working with Speakers from For-Profit Companies**

The National Multiple Sclerosis Society's Guidelines for Self-Help Groups state that self-help groups have the right to choose discussion topics and speakers for meetings, and the responsibility to minimize risk to group members and to the chapter. One of the methods of minimizing risk is to use the Self-Help Group Meeting Disclaimer at every meeting.

In addition to the disclaimer, the National Multiple Sclerosis Society has developed Guidelines for Working with For-Profit Companies that help to ensure that the information we provide is accurate and unbiased. Self-help groups follow those policies. To help you understand these policies, here is a summary of the guidelines that pertain to self-help groups. If you have additional questions, your chapter can give you additional information and guidance about this policy.

- In accordance with the National MS Society Code of Conduct, no staff person, volunteer, speaker, self-help group leader or member shall utilize a self-help group for personal gain.
- Give product information from a pharmaceutical, medical device, research or other company only as a supplement to National MS Society materials. Prior to your meeting, ask your chapter to send you current literature about the topic.
- Lists of self-help group members are kept confidential and are not provided to speakers. Participants may choose to sign a company's mailing list, if it is made clear in advance that it is not required and is not associated with the National MS Society.
- Self-help groups need to provide balanced, accurate information to its members. Self-help groups invite a variety of speakers to their groups. To ensure that information given in your self-help group is accurate and balanced, provide National MS Society literature about all topics, invite speakers with differing opinions to attend your group, ask for input from your chapter about a speaker and encourage self-help group members to ask questions of all speakers.

## **Meeting Ideas**

Self-help groups that have been meeting for a while may find that their members want to expand their discussions to include topics that are not medically focused. You can use the following meeting ideas, topics and discussion questions to explore other aspects of living with MS:

### ***Miscellaneous Ideas***

- Information Exchange
- Have group members research a topic of concern to the group and share the information.
- Pick a topic for each group member to write or think about for 10 minutes and discuss.
- Discuss a book you have all agreed to read.
- Have a professional demonstrate equipment or adaptive devices.

### ***Team Building***

- Make collages about something important (e.g. “What MS Looks Like to Me” using pictures, words, and phrases that have special meaning) and then discuss the collages in the group.
- Celebrate birthdays and personal triumphs of members.
- Have different members sign up to arrange programs and facilitate meetings.
- Discuss group successes and/or concerns.
- Use the *Encyclopedia of Icebreakers* by Sue Forbess-Greene, which contains structured activities that can warm up, acquaint, and energize the group.

### ***Fun***

- Work on a craft project together.
- Give away donated door prizes.
- Play a board game, like Pictionary.
- Show a video, film, or slide show.

### ***Personal Expression and Exploration***

- Practice communication techniques through role-playing.
- Adopt a closing for meetings (e.g. a song, reading, reflection, etc.). Close meetings on a positive note.
- Utilize art materials in meetings to express thoughts and feelings.
- Share personal writings (e.g. stories, poetry, etc.).
- Invite a mental health professional to speak on active listening, conflict management or child rearing.
- Have a special meeting for families.

### ***Physical Health/Stress Management***

- Exercise together.\*
- Do a relaxation exercise.
- Ask a physical therapist or occupational therapist to discuss aids for daily living.
- Invite a music therapist.
- Bring an exercise therapist in to demonstrate Tai Chi, Pilates, Feldenkrais, seated aerobics, or other exercises appropriate for people with MS.\*

*\*Any type of physical exercise requires a waiver from. See your chapter liaison for further information.*

Spending time together outside of meetings can be as important to the development of the group as the meetings themselves. Members can form close, caring relationships when they share time together and it will help them focus on a broader range of issues. Make sure to check the accessibility of all meeting locations, and consider such things as:

### ***Social Activities***

- Go on a picnic.
- Go out for lunch or dinner as a group.
- Spend an afternoon in the park.
- Attend an athletic event.
- Have a holiday gift exchange.
- Hold a potluck dinner.

### ***Cultural/Educational Opportunities***

- Get theater tickets at a group rate.
- Plan a retreat or take a field trip to a history museum, art center, etc.
- Visit another self-help group.
- Attend a National MS Society educational program together.

### ***Community Involvement***

- Volunteer together for your chapter or in your community.
- Form a team for the Walk MS<sup>®</sup>.
- Take valentines to a nursing home with residents with MS.
- Write letters to your congressional representative or local officials together.
- Write to local business about accessibility.

### ***Recreational***

- Invite a Parks and Recreation, Forest Service, or Parks Department staff member to speak about their programs for people with disabilities.
- Go horseback riding at a therapeutic riding center.\*
- Go bowling.\*

*\*Any type of physical exercise requires a waiver from. See your chapter liaison for further information.*

Remember that it's very important to include the ideas and suggestions of group members in the program planning. When members take part in the planning, they will develop more of an investment in the group.

### **Discussion Topics and Questions**

It is sometimes easier to approach the task of “running” a meeting if you are prepared with some questions and topics that can stimulate discussion among group members. Remember that the purpose of asking these questions or discussing these topics is to help individuals think about and share their differing experiences and concerns. Group members' thoughts and comments are not right or wrong; they reflect individual beliefs, coping methods and circumstances.

### ***Relationships with Family and Friends***

- Who has been most/least supportive to me in helping me deal with my MS? What have they done or said that has helped or not helped me? When someone is not supportive or helpful, how have I managed?
- What were my family and friends' reactions to the news that I had MS? How did it differ from what I expected or from what I wanted? Have I been able to shape people's reactions to me? How?
- How do I maintain my relationship with my spouse when I need to give or receive physical care?
- Dealing with family and friends who hear about a therapy or treatment and want me to take it.
- Who is the easiest person to talk to about MS? Why? Who is the hardest person to talk to about MS? Why?
- How do people react to me when they learn that I have MS?
- What do children need to know about MS?
- Dealing with my feelings of inadequacy or guilt as a parent with physical limitations.
- Dealing with family and friends who don't understand my fluctuating fatigue.
- Maintaining a social relationship with my friends when I have physical limitations.
- Dealing with family and friend's expectations when I don't look “sick.”

- Has MS affected my family's communication?
- Communicating my feelings and needs.
- Helping my friends and family to understand.

### ***Taking Care of Yourself***

- Asking for help.
- Saying "no" without guilt.
- How do I maintain my independence?
- Dealing with bowel and bladder difficulties.
- What challenges related specifically to MS have I faced and overcome?
- What challenges have I not handled as well and why not?
- MS and sexuality
- Handling exacerbations and dealing with the unpredictability of MS
- How do I promote "wellness" in all areas of my life?

### ***Personal Feelings***

- What did I used to think about people who had a disability or chronic illness?
- Dealing with differences in disability among self-help group members.
- How did I feel when I was first told that I (or another family member) had MS?
- How do I deal with any stigma I have experienced due to my illness?
- How do I deal with any fear I have as a result of my illness?

### ***Managing Life Changes***

- Generally, how has my life changed? What new values and priorities do I have now that I did not have before?
- To what degree have I learned to accept or come to terms with the illness and what has helped me to do this?
- Traveling and vacationing with MS.
- Aids or little tricks that I have found helpful in my everyday life.
- Considering using assistive devices.
- Dealing with "invisible disability."

### ***Sharing Experience***

- What would I say in a note or a letter to someone (or their spouse) who was facing what I have faced?
- What is the worst problem that a person and his/her family might face as a result of MS?
- Have I learned anything special about life or human nature as a result of my having MS?
- What positive experiences have occurred as a result of having MS?

### ***Physician/Professional Relationships***

- Do I get angry with my doctor? About what? Do I say or do anything about that?
- What are my relationships with my doctor, neurologists and other medical professionals?
- What could I tell my doctor in order for him/her to better treat me? What do I want him or her to know about me in general?
- How has my doctor made me feel especially good or bad?

### ***Employment***

- How has MS changed my work situation?
- Should I disclose my MS at work?
- Asking for reasonable accommodations at work.
- Working around fatigue.

*Adapted from: "Helping the Helper: Program Ideas for Your Self-Help Group" and "Discussion Questions"; American Self-Help Clearinghouse, Denville, NJ; 973/625- 9565.*

## ADVOCACY ACTIVITIES: CREATING CHANGE

Your group may choose to work together as advocates for change. Self-help groups can work towards improving conditions in our society particularly as they relate to access and quality of health care, long-term care and disability rights. Community based examples of advocacy include increasing local accessible public transportation options, getting curb cuts installed to increase sidewalk accessibility and increasing affordable community based long-term care options in your community. Public policy advocacy involves efforts to influence legislation and regulations in these areas at the federal, state and local levels to benefit people with MS and other chronic illnesses and disabilities.

Grassroots advocacy is at the center of the self-help group involvement in public policy advocacy. Grassroots advocacy attempts to address the concerns of large numbers of people by identifying broad issues and problems, finding ways to address those issues and problems, influencing decision-makers (elected officials, government employees, business leaders and other community leaders) and mobilizing large numbers of people in support of proposed solutions.

Why become grassroots advocates? Participation allows individuals to take control of their lives in an effort to improve their situation and, at the same time, help other individuals who live with MS and other disabilities. Activity can actually change government laws and regulations to improve public policy. Government responds to those who voice their concerns.

### Ways for You and Your Self-Help Group Members to Become MS Activists

#### 1) Join the MS Activist Network

As a member of the MS Activist Network, you will receive “action alerts” via e-mail. These alerts will keep you updated on important political issues and prompt you to take action at the local, state or federal levels to improve the quality of life for people living with MS. Go to <http://www.nationalmssociety.org/msactivist> to join.

#### 2) Meet with a legislator

Visiting their district office or inviting them to one of your meetings can be very effective. Legislators work for us and they want to hear from us. WE are the credible experts on how MS can affect an individual, a family, a friend and a community.

#### 3) Call a legislator

Typically, we call legislators when there is a specific piece of legislation that is being considered and we want them to either support or oppose a bill. If a legislator receives 5-7 notifications about an issue it may move up on his or her priority list.

4) Write to a legislator

Local and state legislators appreciate receiving hand written notes from their constituents. At the federal level, due to screening procedures, regular mail is not delivered in a prompt manner and therefore is not effective.

5) Talk to family, friends and communities

Talk with people about the issues; why they're important to you and how they can help make a difference. Hold a community forum or town hall and invite a guest speaker to talk about a particular topic.

6) Write a letter to the editor

Write a letter to your local paper about MS; what it's like to live with MS in your community and how others can make a difference to improve the quality of life for people with MS.

7) Volunteer at events – recruit members for the MS Activist Network

Volunteer at your local Walk or Bike event – encourage others to sign up for the MS Activist Network.

8) Follow state and local politics

Assign one of your group members to be an advocacy liaison or a “district activist.” Read about what's going on in your communities, watch the news, listen to the radio and communicate with National MS Society staff about ways we can either be involved or take a stand as an organization.

9) Address local issues

As a group, identify an issue that is in your community. Create an action plan to address that issue and ask National MS Society staff to support your efforts.

The above activities are part of an advocacy toolkit designed especially for you. Please reach out to your chapter staff to receive a copy and discuss how to utilize the kit with your group.



## STRATEGIES FOR MANAGING DIFFICULT SITUATIONS IN THE GROUP

The never-ending challenge to self-help groups is to help members through the worst of times without undermining the group or endangering a life. This is no simple task. Although there are no absolutes, groups have found some effective strategies for assisting members when they are in distress, or even in a suicidal crisis.

### **Active Listening**

A key feature of the helping relationship is active listening. Active listening implies that an individual is actively attending to and thinking about what is being said by another person. While it may sound simple, it is a difficult skill to master. However, it is a skill that can be learned and improved upon by most of us.

There are many ways that self-help group members help each other including sharing information and personal experiences, offering emotional support, socializing and problem solving. Effective, active listening helps to make each of these activities a more meaningful experience for all involved.

Here are some techniques for active listening:

- **Restating**. Repeating what a person says using the same or slightly different words. This is a very concrete way of indicating you have heard what the person said.
- **Questioning**. Asking gentle, probing questions to clarify or obtain more information conveys active listening. Be careful not to appear to be cross-examining or questioning the truth of the statements.
- **Summarizing**. Stepping back and looking at the big picture (i.e. putting the current conversation in context and reviewing all that has been said). This helps the speaker gain perspective and perhaps re-focus.
- **Reflecting and validating feelings**. Identifying what you perceive to be the feelings underlying what is being said (e.g. “It sounds like you were scared at that moment. . .”). This helps the speaker identify his/her own feelings and helps him/her feel okay about having a particular feeling. It indicates you understand why he/she might feel that way—even if you might have felt differently.

Practices of a good listener include:

- Be ready to listen, observe and understand. Don't be quick to reply, contradict, refute or argue.
- Note non-verbal communication (e.g. body language, tone of voice, facial expression).
- Don't jump to conclusions.
- Be empathic. Try to put yourself in the speaker's shoes, seeing the world as he/she sees it, whether you would see it that way or not.
- Put aside your own opinions for the time being. You cannot listen actively at the same time you are forming your opinion or reply.
- Be patient. The average person speaks at about 125 words per minute but can listen to about 400 words per minute (and some people with MS may speak more slowly). Give the speaker time and don't jump ahead of him/her. What the speaker says next may not be what you expected. Don't finish the speaker's sentences.
- Show interest and alertness. Use your own facial expression and body language to indicate you are fully engaged and present in the moment. Establish comfortable eye contact without staring.
- Don't interrupt.
- Don't be a selective listener (e.g. hearing only what you want to hear or making value judgments).
- Convey an attitude of acceptance.
- Try not to use the term "should" very often. It implies judgment.
- Don't be distracting by cleaning your fingernails, fidgeting, fiddling with a pen, or be distracted by the clock or other things happening in the room.

### **How to Minimize Distress in Your Group**

- Have ground rules that spell out what is expected behavior for your group. Remind the group at the beginning of each meeting by having a member read them.
- Make sure that your meeting place feels safe. Check with your group about whether the location provides a calm and non-threatening environment.
- Utilize individual members' strengths and resourcefulness. Allow people to take responsibility for providing specific kinds of assistance. For example, some people are one-to-one support people, others can keep the group calm and some know how to access community resources. Don't force a person into doing a job that is overwhelming or uncomfortable.
- Use your chapter liaison as an advisor to the group. They can provide insights, support, technical information, problem-solving and access to resources that might otherwise not be available to the group.

- Deal with priorities. At the beginning of each meeting, when persons introduce themselves, allow each person the opportunity to bring up any specific issues that they would like to discuss at the meeting. These issues can be recorded, perhaps on a flip chart, and may then be adopted as the meeting's agenda. It will alert the group to any serious problems or issues that require attention, as well as provide some assurance that the group is meeting the real needs of its members.
- Avoid falling into the advice-giving trap of assuming that because you also have MS, you fully understand what another person is going through. Listen and ask questions.
- Don't feel compelled to "have the answer" or to "fix" a person's problem. The reality is that what people find truly helpful is someone listening with their full attention, someone who is interested in understanding how they feel and someone who respects a person's right to feel the way they do, whether or not they agree. Rely on questioning, clarifying and constructive feedback as problem-solving tools.
- Develop coping strategies that minimize disruption without degrading a person. For example, one group passes around a floor tile. Whoever is speaking holds the tile until he/she is done speaking and then passes it on to the next person. If someone interrupts, the group reminds him/her that the speaker has the floor.
- Avoid harsh confrontations that make people angry, defensive and hurt, and more than likely, cause a person not to return to the group. One group leader, who was very frustrated by members who monopolized the meetings, took them aside and thanked them for their contributions to the group. The leader then asked the monopolizing member if they would help "bring out" the more quiet members. From that point on, they focused their attention on getting other people to share and ceased monopolizing group discussions—mission accomplished without hard feelings and without losing a valued group member.
- "Don't leave tonight with more pain than you brought with you," is how one group leader opens the meeting. At the end of the meeting there is a ten-minute "check in" with people to give them the opportunity to share any burning issues. At this point, members can "leave" their unresolved problem or pain at the meeting, or identify persons available for one-to-one support in-between meetings.
- Build trust. If you are concerned about someone, express it to him or her through phone calls between meetings or by inviting them out for a cup of coffee after a rough meeting.
- Be reasonable. Some more established groups have found it helpful to work with chapter staff and leadership volunteers to negotiate problem situations that arise within the group or to resolve grievances such as suspension of a member who comes to meetings under the influence of drugs or alcohol.

*Adapted from: "Strategies for How to Cope with Distress and Manage a Crisis in Your Group" by Margaret Duthie; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565*

### **Group Problem-Solving**

This approach is best used when a problem or situation is concrete and needs new ideas or approaches for its solution. It works well in a small group of 10–15 people, on problems that are narrow rather than broad or are specific parts of a larger problem. The leader who conducts these sessions must know and observe the ground rules. The process can take about 35–40 minutes.

- Define the problem. Make sure it's solvable or posed as a solvable problem. If the problem is too large, keep re-stating it until you narrow it down to something small you can deal with, perhaps a part of the original problem.
- Propose solutions. Ground rules for this process:
  - Suspend judgment. Don't criticize or reject any ideas yet.
  - Freewheel. Express all ideas, no matter how wild.
  - Quantity. Generate a large number of ideas.
  - Cross-fertilize. Pick up on one another's ideas; improve upon them.
  - Evaluate solutions and weed out. This is the time to be more critical and realistic, but be on the lookout for any new ideas that come up at this point.
  - Rank order the remaining ideas. Decide which one should come first, second, etc.
  - Select the best option and assign tasks. Develop a plan for implementation, including who will do what by when. Also, decide how to evaluate success.
  - This brainstorming technique can help the group reach consensus on how to deal with a problem or situation in the group.

*Adapted from: "Group Maintenance Strategies: Ways to Strengthen Your Group When Problems Arise" by Anne Douglas; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

### **People Who Disrupt the Group**

If you feel uncomfortable with something that is being said or done in your group, chances are other members also feel ill at ease. Sometimes an individual member's behavior creates discomfort in a group, for example, monopolizing the discussion, remaining silent or breaking confidentiality. Although it may feel uncomfortable to address disruptive members, remember that the other group members are relying on you to do so. Your focus needs to be what is best for the group as a whole, not what's best for the particular member.

It's helpful to have group guidelines that all members are aware of and can refer to when someone is becoming a problem. These guidelines usually specify the behaviors that the group supports and those that it finds unacceptable. Some groups review their guidelines briefly before each meeting; this keeps fresh in members' minds what the group has decided are appropriate ways to act in the group.

### **Talkative member who monopolizes meeting**

- Remember that some behaviors may be due to a person's MS. Sometimes MS slows the cognitive process, making it difficult for a person to complete their thought in a short amount of time. Speech impairments can make communication taxing, both for the speaker and listener. Make sure everyone is given enough time to communicate effectively.
- Have a "round robin" at the beginning of the meeting, giving members an opportunity to talk about anything that is a pressing issue for them at the moment. This can alert leaders and members to individual needs that may require some meeting time in which to be addressed.
- If time is a problem for your group and you find that a few people consistently monopolize the discussion, there are ways to handle it. The group can have a facilitator/time keeper. A graphic and symbolic way to handle it is to use an egg timer. The person speaking holds the egg timer and can talk as long as sand is running through the egg timer. When the sand has run through the egg timer gets passed on to the next person whose turn it is to speak.
- The leader, or a group member, can pick up on something the person has just said, use it for the beginning of the next topic and ask a question of the group or another member with whom they have made eye contact: "That's a good point, Bill. (Turns to Mary) Mary, have you ever. . ."
- It may be necessary to interrupt: "Joan, I know this is something that is really important to you, but several others have thoughts they want to share. Bob, what are your feelings about this topic?"
- The leader or a group member can say: "I'm concerned that John didn't have an opportunity to speak. Let's get back to his concern."

### **Distracting side discussions**

- The leader or a member can address a question to one of the conversationalists or ask them to share their comments with the group.
- Remind the talkers of group rules about respectful behavior and/or only one person speaking at a time.

### **Authoritarian advice-giver**

- For the one who knows everything, one strategy is to use this person's assertions for a springboard. "John, many of us used to think as you do, but our experience with \_\_\_\_\_ (or a book, or an article) helped us change our thinking a little."
- Remind everyone that self-help group members don't judge treatments, because everyone's MS is different.

### **Silent member**

Silence is not necessarily a deficit. New members may not feel comfortable at first expressing feelings or ideas in front of people whom they have just met and may need a few meetings before they feel free to talk. You might consider having a private conversation with them to make sure that they feel comfortable to speak up, if they would like to do so. Some people who aren't actively participating may still benefit from attending the meetings and listening to other's experiences.

### **Aggressive member**

Attacking behavior is disruptive to a group and can be a deterrent to participation and even attendance. The group as a whole has a responsibility to hold such behavior in check and use the energy of attack in more constructive ways. The aggressive or attacking behavior may prompt from others either retreat or an equal force of energy, attacking back. Responses that are calm may be the most helpful way to neutralize attacking behavior.

Remind members of your rule regarding respectful behavior. If the behavior continues, contact your chapter for guidance.

### **Passive-aggressive member**

Sometimes, someone acts passive, but is really aggressive. The behavior—verbal and/or non-verbal—is often biting or snide. Possible motivations are:

- Person is annoyed with one or more group members or with leader.
- Person feels personal needs are not being met.
- Person seems, or is, preoccupied with an issue outside the meeting scope.
- Person has a hidden agenda.
- Person wants to be the center of attention.
- Ask if the member has a particular issue he or she would like to discuss.
- Talk to the person outside of the meeting. In general, to prevent disruptive behaviors, structure the meeting so everyone focuses on agenda items rather than personalities and allow group members to express personal goals for group and/or the meeting.

### **Other techniques the leader might use:**

- Ask directly if the individual wishes to discuss a particular issue.
- Ignore the situation if it does not negatively affect the group.
- Use humor that encourages, yet does not embarrass, the individual.

*Adapted with permission from: "Difficult Behavior Patterns," Chapter 10 in "Energetic Meetings: Enhancing Personal and Group Energy and Handling Difficult Behavior" by Jeanie Marshall; Jewel Publishing House, Santa Monica, California; 1994.*

### **Encouraging Expected Behavior**

If a particular member's behavior is regularly disrupting the group, this tool can help you bring the behavior to his/her attention and ask for a change. During a private meeting, let the member know of your concerns and expectations and together, generate a mutually agreeable solution.

Use this recipe for "BEER" to give corrective feedback:

- **Behavior**. Describe the behavior that is not working.
- **Effect**. Describe the effect it is having on the group.
- **Expectation**. Outline the behavior you want to see.
- **Result**. Describe the results of the new behavior on the group and its members. Also describe what will happen if the behavior doesn't change.

### **Recognizing and Managing Your Own Personal Issues**

There are some challenges associated with being a self-help group leader that might occasionally interfere with your effectiveness in the leadership role.

Even self-help group leaders can have a bad day. There may be times, for example, when you are feeling so fatigued or otherwise uncomfortable from your own MS that you have little to give to others in the group. Your wish and need to be on the receiving end of everyone else's help and support may temporarily overwhelm your ability to lead.

Issues or concerns raised by other group members may cause you distress. You might, for example, become anxious when someone in the group talks about marital or financial problems that are similar to your own. Or, a person may discuss a symptom such as sexual changes or cognitive problems, which are particularly frightening or difficult for you to talk about.

You may find yourself feeling very uncomfortable with the emotions expressed by another group member, for example, when someone becomes very tearful or angry. It is sometimes difficult to know how to respond to a person in distress, particularly if the feelings being expressed are either very similar to, or very different from, your own.

When your feelings are similar, you may worry about your ability to respond effectively without getting caught up in your own issues. When your own feelings are very different, you may find yourself feeling impatient or even resentful, without the ability to empathize.

There may be a group member whom you find particularly frustrating or annoying. This can occur, for example, with a very needy person who monopolizes group time looking for everyone else to solve his or her problems and rarely has the energy to give to anyone else.

Occasionally, you may find yourself in a conflict with a chapter staff member or volunteer, or you may disagree with a decision made by chapter leadership. It may be tempting to bring these issues to other group members, but that may unfairly damage those group members' relationships with the chapter.

Discuss any conflicts and disagreements with your chapter liaison, the chapter programs director or a volunteer member of the Programs Committee or Board of Trustees and continue to work toward resolution.

Your role as a support group leader should not take the place of, or even take precedence over, your role as a group member. Your ability to give effectively to the group will depend, in large part, on the degree to which your own needs are being met within the group setting. Therefore, paying attention to your own feelings and needs, even while you support the efforts of others to deal with theirs, will enhance your personal well-being and increase your effectiveness as a self-help group leader.

We strongly recommend that every self-help group have co-leaders. Co-leaders can provide invaluable support for one another in a variety of situations:

- You and your co-leader can share the ongoing tasks and responsibilities so that neither one of you feels over-burdened.
- You can back each other up in the event that one of you is having an exacerbation or feels too exhausted to attend a meeting.
- You might ask your co-leader to assume the primary leadership role if you were having a difficult time emotionally and need to be able to talk about it over the course of one or more meetings without having to be concerned about leadership responsibilities.

Co-leaders can work cooperatively to handle a difficult group member who is disruptive or tends to monopolize the discussion. Although the entire group shares the responsibility for supporting the group rules, this enables leaders to share the burden of enforcement and reduces one-on-one confrontation.

There are also resources outside the group that can help in the event that you begin to feel overwhelmed. You should feel free to contact chapter program staff for support and guidance if the leadership role becomes too distressing. They can help you deal with problem situations within the group or with concerns you don't feel comfortable addressing directly to the group. In the event that you find yourself confronted with feelings or issues that you don't feel comfortable sharing in the group or with chapter staff, you might consider discussing them with a professional counselor. It is not at all unusual for group leaders to



find themselves wanting time and space to sort out some personal issues so that they can be more effective in their leadership role.

Keep in mind that your participation in the group is voluntary. The essential motivation for your participation needs to be that you find it a positive experience. As a result of your participation in a self-help group, you should feel good about yourself and empowered to confront the challenges posed by your MS. If the leadership role begins to interfere with the benefits and satisfaction you derive from the group, you may want to consider stepping out of that role. You may even decide that you need to take time away from the group altogether. Always feel free to discuss any or all of these issues with your chapter program staff.

### **Dealing with Anger in the Group**

When trying to understand people's anger in self-help groups, it might be useful to think of two different kinds: situational and underlying.

#### ***Situational Anger***

Situational anger is in response to something that happens to someone, such as a loss, a diagnosis of multiple sclerosis, a broken promise or a perceived threat. As such, it has an identifiable cause and a focus or object—who or what the person is angry at. By far the more common type (and a normal phase of adapting to multiple sclerosis), situational anger is easier to deal with and in most support groups should be an expected and workable part of the self-help process. Although it is usually directed at people, it is almost always about events or situations, either outside or within the group.

#### **Anger about Something Outside the Group**

A group member may react angrily to comments someone has made or to a discussion topic, but in reality their anger may stem from a situation outside of the group. Consider the example of a group member who is angry because her family does not understand fatigue caused by MS.

Usually, the best response to this kind of anger expressed within a support group is to let her have her anger. In the present example, don't try to convince the member that she is not angry or that she shouldn't be angry. Acknowledge the emotional reality of the anger and, if possible, validate it by indicating that you, too, would be angry if you were in her situation.

Once a group member realizes that he or she doesn't have to be arguing with you about the fact of their anger, or their right to be angry, then the "real" object or focus of this anger can get the attention that it deserves. Details can be discussed and strategies planned for how the group member might deal with the person or situation. Other group members can share their similar experiences and insights.

In some cases, what begins as anger gives way to a different emotion that the group member was not initially aware of. A frequent one is fear, for example, of what might or might not happen in the near or distant future. Others may include guilt over something in the past or deep sadness over a realization or a loss that is difficult to accept. Thus, by being allowed to “have” their anger, people can often get “past” it to other feelings that may be difficult, but important to deal with directly.

### **Displaced Anger**

Sometimes, although the group member is in fact angry about something happening outside the group, this anger gets displaced onto another person in the group who somehow triggers the anger and thus becomes its target. The classic example of this is the man who feels unfairly treated by his boss at work and consequently goes home, yells at his wife, hits his children and kicks the dog.

The best strategy for dealing with this kind of mutually misplaced anger is to: (1) Step in as an observer who cares for both parties and (2) Try to point out what you think is going on. Using what each person has said about themselves in prior group meetings, your goal is to convey that you don’t blame them for feeling the way they do, but that it’s not really each other that they’re angry at! On the other hand, be extremely careful not to accuse someone of displacing anger when in fact the person is genuinely angry with someone in the group for something that has gone on in the group.

### **Anger about Something Inside the Group**

Sometimes, especially in groups whose members get to know each other well over time or through contact outside the group, anger comes up that is genuinely between members of the group. This can occur when members of the group have a disagreement over group business and it can occur when someone in the group takes a strong disliking to the way someone else in the group is acting or being dealt with.

If you decide that the problem is group business (as opposed to something that shouldn’t be addressed in the group) then you have the difficult, but rewarding, task of trying to help people hear and acknowledge each other’s angry messages and opposing viewpoints . . . in other words, helping them to “fight fairly.”

Here are some suggestions for accomplishing this:

- Clarify the issue. What exactly is each person angry about? Can each person state clearly his or her own viewpoint and how it differs from the other person’s? Sometimes a simple misinterpretation is at the root of the problem.

- Ensure group back-up or support. If each party in an argument feels some degree of support or understanding from some people in the group, the intensity of their anger may be reduced somewhat because they won't feel so completely alone.
- Encourage "I" statements. When I'm talking about how I feel or what my experience is (even when in response to something you said or did), you are less likely to be further angered than if I make statements about you and your behavior, passing judgment on you.
- Allow people to finish statements without interruption. Keep discussion focused on one issue at a time.
- Encourage and model active listening. Occasionally restate what each party is saying, or ask them to do it, to make sure people are hearing each other's messages.
- Take a short break. When things feel out of control, it may be useful to ask for a moment or two of silence, or perhaps to encourage a stretch, or a coffee break. This can give everyone a cool down period.
- Invite others to help out. Sometimes, especially when it feels like things are at an impasse, it is helpful to get the feedback of others in the group who are not directly involved. Watch out for scapegoating, however, or for extremely uneven side taking. If this occurs, make sure someone speaks up for the underdog or at least touches base with him or her. Example: "Well, it seems like a lot of people agree with John . . . [to Mary] does that make you feel kind of alone?"
- End the meeting with a round robin. Whether or not there is still anger in the air, it might be useful to give people in the group a chance to have a "last word" or two about what happened during the meeting and about what they might want to see happen next time.

### *Underlying Anger*

Underlying anger, on the other hand, can be thought of as a long-term and generalized state of hostility towards the world or a major part of it (towards doctors, for example). It usually stems from a lifelong set of experiences that, occurring individually, might have produced situational angers in the person, but over time has built up a deep and stubborn rage that "unfairly" targets people or situations that have little to do with it. Underlying anger resists efforts to diffuse it by lay people and professionals alike.

How can you tell when anger is not just situational, but underlying? One clue would be its persistence. If someone seems to be angry all the time, meeting after meeting, and seems unable to accept repeated efforts on the part of other group members to help, that could be one sign. Another would be its intensity. When a person's angry responses consistently seem way out of proportion to what the situation is, it could be that the person is not really

reacting to the immediate situation, but rather to a long history of circumstances that are simply beyond the reach of the group's help (e.g. unresolved anger about having MS).

An important factor not to be overlooked is people's reactions to the person in question. If several group members share with you a concern about this individual, saying in essence that he or she seems "frightening," "out of touch with reality," or in some other way "not reachable" in his or her anger, you have a good indication that the person's anger is threatening the group and you should do something.

An initial approach might be to have one person from the group speak to the "angry" person privately and see if direct contact helps.

- How does the person react to that?
- Does the angry behavior in the group change afterward?
- Does the person come forth with an explanation that makes it seem to be worth continued efforts to help him or her?

Sometimes a referral to a counselor is warranted as an adjunct to continued group membership. Consult with your chapter liaison about the situation.

Obviously, if none of this works then the serious question of continued attendance in the group arises. Underlying anger can be extremely destructive in self-help groups, hurting both individuals and the group as a whole. Please refer to Standard #5 to review information about denying participation in a group to disruptive individuals.

*Adapted from: "On Dealing with Personal Anger in Self-Help Groups" by Andy Bernstein, EdD; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565.*

## **HANDLING A CRISIS SITUATION**

A crisis can come in at any time. A person with MS may come to share a physical or emotional abusive situation, an eviction from his or her residence, or even the wish to end his or her life or someone else's. Or, the entire community may be facing a crisis of some kind. Although a self-help group is not designed to be a crisis center or an emergency service, it may be the only place a person with MS feels he or she has to talk about the problem. If this is the case, it becomes the role of the group leader to help the person connect to a more appropriate resource.

### **ASSESSING AN EMOTIONAL CRISIS**

A group member who is feeling frightened or overwhelmed may become very emotional in the course of a conversation that starts out very calmly. Sometimes this response is simply a reaction to being in a friendly, supportive environment with people who understand. Having come to share a concern, the member may be so relieved to be understood that he or she wants to continue talking. The member may begin to cry and feel very embarrassed about this loss of emotional control. In this situation, the appropriate response is to remain calm and ask, in a matter-of-fact manner, if there are other issues or questions he or she would like to share. Tears are normal and not necessarily a sign of depression or crisis.

If the member seems to respond to this question, and is able to regain control, you can listen quietly until you have a sense of the problems needing to be addressed. The group's calm and caring presence will often be enough to help the member get into the problem-solving mode. As a group, you may be able to identify a needed resource or referral, or answer questions that have been causing the person a great deal of upset. Most people will respond well to this kind of interaction and be ready to take action, knowing that a helpful connection has been established.

Occasionally, however, you may find that the group member either cannot calm down or begins to talk about a problem that seems to require emergency intervention. The group member may even talk about feeling quite desperate or ready to give up. At this point, you will need to decide whether the member seems to be in immediate, life-threatening danger or in danger of hurting someone else.

### **PREPARING TO RESPOND TO A GROUP MEMBER EXPRESSING SUICIDAL THOUGHTS OR FEELINGS**

Undoubtedly the most frightening and challenging type of crisis situation involves the person who sounds very depressed or is expressing suicidal thoughts or feelings. This type of

group member makes us feel that the person's life is in our hands and that the outcome is totally dependent on what is said or done.

We worry that we won't know what to say or that we will say the wrong thing. We are afraid to question the person about suicidal thoughts or feelings lest we plant a new idea or inadvertently cause the person to act in a self-destructive way. The important thing to remember is that by communicating our willingness to listen we are providing a lifeline to someone in distress. Our most useful tool is our genuine concern. It can enable a person to reconnect with life when he or she had given up all hope of that being possible.

In order to feel prepared to respond to this type of stressful call, it helps to:

- Understand the most common reactions experienced by people living with chronic illness.
- Recognize some of the emotional changes caused by the disease process itself.
- Be able to distinguish them from signs and symptoms of a serious depression.

### **Common Emotional Reactions to the Disease**

- Initial reactions to being diagnosed with MS usually include some combination of disbelief, shock, fear and possibly even relief. Some people simply do not believe the diagnosis and continue to search for an explanation for their symptoms that is less difficult to accept. Others may feel shocked into numbness so that they find it difficult to feel anything at all. For those people who have heard only about the most disabling cases of MS, the initial reaction may be fear. Anyone who has lived for months, or years, with unexplained symptoms, or has been told that the problems are all emotional or psychological, may actually feel relieved to finally have an answer. Others may be relieved that their illness isn't a brain tumor or some other fatal disease.
- Longer-term reactions. Other reactions to the MS gradually emerge as the realities of the illness begin to make themselves known. These reactions tend to be determined by the kinds of symptoms the person is having and the degree to which those symptoms interfere with the person's life. Thus, for someone who works as a store manager or loves to dance, problems with walking might be the most distressing. For an author or teacher, ambulation problems might seem less frightening than cognitive changes involving memory or problem-solving.

In general, however, there are some feelings that everyone with MS tends to experience at one time or another—namely anxiety, sadness or grief, anger and guilt. The important thing to remember is that there is no particular order or progression to these feelings. They are likely to come and go as the disease ebbs and flows.

### ***Anxiety***

One of the hallmarks of MS is its unpredictability. People tend to feel anxious or nervous when they do not know what is going to happen next. Feeling out of control also makes people feel anxious. Neurological changes that affect vision, bladder and bowel control and the ability to walk can feel threatening to any person's sense of control and autonomy.

### ***Sadness and Grief***

Being diagnosed with a chronic illness requires a person to think a bit differently about him- or herself. Almost like a lifetime jigsaw puzzle, one gradually pieces together a self-image. MS is a new piece that somehow needs to be inserted into the puzzle. This kind of change makes people feel sad, and grieving over the lost sense of self is a necessary and important part of building a new self-image that includes MS. Any time a symptom interferes with a person's ability to do something that is important to him or her, some of this normal grieving will take place.

### ***Anger and Resentment***

Anger and resentment are also common reactions to a chronic, unpredictable disease. People resent the intrusion into their lives of something over which they have so little control. Some wonder what they could have done to deserve this; others find themselves angry at the doctor or at God for letting it happen to them. They may feel anger toward those around them whom they perceive as healthy and free of problems. They may also feel angry at themselves when they cannot do something that they used to be able to do so easily.

### ***Guilt***

If and when MS interferes with a person's ability to fulfill various work or family responsibilities, he or she may also experience guilt. No one wants to let down or disappoint family members or colleagues. One of the ongoing challenges for a person living with MS is how to find a comfortable balance between caring for him- or herself and meeting the needs and demands of others.

## **Emotional Changes Caused by the Disease**

### ***Mood Swings***

MS can cause structural changes in the brain that increase the risk of abrupt changes in mood and emotional expression. Some mood swings may also be caused by medications, especially high-dose steroids.

Regardless of the cause, abrupt changes in mood can make family life stressful and unpleasant for all concerned. People experiencing these uncomfortable mood swings can be treated very effectively with a combination of psychotherapy and medication.

### ***Pseudobulbar Affect***

Pseudobulbar affect, a condition in which brief episodes of laughing and crying can occur without any obvious precipitating event, seems to be associated with lesions in the limbic system, a group of brain structures involved in emotional feeling and expression. Unlike the mood swings described above, the laughing and crying displayed by someone with pseudobulbar affect may have nothing to do with how the person is feeling at the time. The laughing or crying may start for no particular reason and then be very difficult to stop. Pseudobulbar affect can sometimes be helped with certain types of antidepressant medication.

### **Clinical Depression—A Reaction to the Disease and/or Part of the Disease**

In addition to these emotional reactions and changes, individuals with MS can experience significant episodes of depression. In fact, clinical depression is more commonly seen in MS than in the general population or in other chronic disease groups. The evidence suggests that depression in MS can occur as a reaction to the persistent stresses and losses associated with the disease, as well as being a direct result of MS-related changes in the brain. In other words, depression can be a response to, or a symptom of, multiple sclerosis. Regardless of the origins of the symptoms, however, depression can usually be treated effectively with some combination of antidepressant medication and psychotherapy.

Unfortunately, too many individuals with MS do not receive timely or adequate treatment for depression. This may be because they fail to recognize the feelings they are experiencing as depression or because they are reluctant to seek help for emotional problems.

Clinical depression, also known as a major depressive episode, typically includes at least five of the following symptoms, occurring together for the same 2-week period:

- A depressed mood for most of the day every day
- Diminished interest or pleasure in any or all activities
- Significant weight loss or weight gain (more than 5% in a month)
- Significant change in sleeping habits, including much less or much more than usual
- Recurrent thoughts of death or suicide, sometimes including a specific plan for ending one's life, or an actual attempt to do so
- A slowing or speeding up of motor function (i.e. psychomotor retardation or agitation)
- Fatigue or loss of energy nearly every day
- Diminished ability to think or concentrate
- Feelings of worthlessness or excessive or inappropriate guilt (not merely self-reproach or guilt about having an illness)



A review of this list reveals that several of the symptoms of a major depressive episode are relatively common in MS (e.g. motor slowing, fatigue, diminished ability to think or concentrate, sleep disturbance and feelings of worthlessness or guilt). This overlapping of symptoms can make it difficult for people, including family members, professionals and individuals with MS themselves, to recognize the presence of a severe depression. As a result, the person with MS may reach a point of crisis before receiving the necessary help for his or her depressive symptoms. It is at this point of crisis that the person may reach out to the National MS Society.

A depressed mood and loss of interest or pleasure in everyday activities are the hallmarks of depression. Suicidal thoughts or feelings may also be present, but are not always so. Additionally, the presence of suicidal thoughts or feelings does not necessarily mean that a person is going to act on them. People with a chronic, progressive disease can contemplate the difficulty of their lives, and wish for the struggle to be over, without having any intention of harming themselves or ending their lives. Nevertheless, we cannot ignore the risk of suicide in a seriously depressed person and need to be alert to the verbal and non-verbal cues that are given to us.

### **ASSESSING A GROUP MEMBER'S RISK OF SUICIDE**

The following guidelines will help you in the event you need to make a suicide assessment and intervention. Although you may go through your entire career as a volunteer of the National Multiple Sclerosis Society without having to deal with a suicidal situation, it is important for you to review these guidelines periodically so that you will feel at least somewhat prepared.

In your group or individual dialog with an individual you may find yourself having to determine if an individual is experiencing a life-threatening crisis that requires immediate attention. As you are talking to the person here are some particular things to look for:

- Change in behavior. The person may report losing interest in people or activities that he or she previously enjoyed. Formerly outgoing and sociable, the person may have gradually stopped visiting with friends, attending meetings or talking on the phone. The person may report emotional exhaustion (e.g. "I just don't have the energy to be with people anymore").
- Change in personality. The person may report feeling irritable, anxious or sad, while at the same time sounding apathetic about life and the future. He or she may describe a preoccupation with memories of life before MS and express hopelessness about life ever being "normal" again.
- Change in eating/sleeping habits. Sleep disturbances, including early morning awakening, insomnia, and excessive sleeping, are very common in depression.

Since sleep disturbance is also very common in MS, it is important to listen for indications of overall changes in sleep patterns that seem unrelated to physical symptoms such as frequent urination or painful spasms. Depression can cause eating disturbances as well, including compulsive eating or decreased appetite leading to significant weight loss.

- Change in speech patterns. A depressed person may talk more slowly than usual, as if the energy to keep up speed is gone. Since speech can also be slowed by fatigue and other MS-related neurological changes, it would be important to find out whether the altered speech pattern had been acknowledged by the treating physician as a symptom of the disease.
- Feelings of despair or isolation. Feelings of despair and isolation are apparent in the following comments: “No one can possibly understand how I feel,” “I will never feel any differently,” “The world would be better off without me,” “I’m no good to anybody anymore,” “I feel like a drag on my whole family.”
- Drug or alcohol use. The use of substances impairs a person’s impulse control, including the impulse to commit suicide. The individual who is using substances is at far greater risk of harming him- or herself than the person who uses no substances.
- Sudden lifting of severe depression. Paradoxically, the risk of suicidal behavior may be greatest at the point when a severe depression begins to lift. A person who has been severely depressed may not have had the emotional or physical energy required to act on the suicidal feelings. With the lifting of the depression, more energy is available to carry out the act. In addition, some people experience a lifting of severe depression once they have made the decision to end their lives. Therefore, it is important to listen for clues indicative of relief over a decision that has finally been made.

## **HOW TO PREPARE FOR CRISIS SITUATIONS**

Together with your chapter, develop an action plan for dealing with a distressing situation or crisis before it happens. Have it available and follow it. Be aware that many crisis situations are likely to occur between meetings during phone conversations. (Your chapter may have specific procedures for you to follow.)

- Keep a list of phone numbers for appropriate resources in the community such as: helplines/hotlines, hospital emergency room, psychiatric emergency services, screening centers, counselors who specialize in the issues your group addresses, ambulance services, community mental health centers, police, etc. Bring it to your meetings, keep a copy next to the phone and make copies available to the rest of the group. You should update this list with your chapter liaison periodically.
- Invite your chapter liaison or other trained professional to speak to your group about strategies for handling distressing/crisis situations.

- Know your limits. Some problems do require other forms of intervention. Referring a member to other resources is not a failure on the part of the group; it is responsible decision-making.

## **HOW TO RESPOND TO A SUICIDAL PERSON**

With all this information about suicide, you may be concerned about what you would actually say or do if the person talks about committing suicide. Unfortunately, there is no perfect script for this kind of situation. The following steps can serve as a guide for handling a crisis call, and cueing for important information that should be gathered from the person.

### **Assessment Stage**

#### **Step 1: ASK**

If you suspect the person is suicidal, it is important to ask, “It sounds as if you are thinking about suicide or hurting yourself. Have you had thoughts like this?” Remember, you are not giving the person the idea or putting the suggestion into his or her head. By bringing it up in the first place, you are being invited to ask questions.

#### **Step 2: FIND OUT WHAT IS GOING ON**

Try to gather as much information as possible, including the person’s name, address, age, and telephone number. This is information that will be necessary to give your chapter liaison and/or the police if the act of suicide is imminent.

Ask, “What has happened recently that you are thinking about suicide?” Listen for recent losses and changes, as well as anticipated events.

#### **Step 3: FIND OUT SOME HISTORY**

If the idea of suicide has been brought into the conversation, it’s important to ask:

- “Have you ever felt this way before?”
- “What was going on during that time?”
- “What happened then that allowed you to keep going?”

People attempt suicide for many different reasons. Most, however, are not seeking death. More frequently, suicide is seen as a way of ending pain, or a way out of helplessness or shame.

#### **Step 4: FIND OUT IF THE PERSON HAS A PLAN**

It is important to ask if a plan has been made—the more thought-out the plan, the higher the risk. It is important to listen between the lines to the response. You will learn important information from the quickness of the response as well as from the words the person says. If there is no specific plan, the person is probably not in immediate danger.

Ask, “Have you thought about how you would do it? Do you have a plan? What would you do?”

#### **Step 5: DETERMINE IF THE PERSON CAN ACCESS THE MEANS TO IMPLEMENT THE PLAN**

Once the plan has been described, it is important to determine whether the person has the means to carry out the plan. Ask, “Where will you get the pills (gun, knife, rope, etc.)?” If there is a plan as well as means, the risk is high and imminent. The most important strategy is to keep the person talking as long as possible. While doing this, try to assess impulse control. You are trying to determine whether the person has the ability to delay acting on the urge to carry out the plan. Try to make a contract to put the gun, pill, etc., out of sight while you are on the phone together. The contract is a verbal agreement that the person promises to abide by while you are getting help. If you are at all concerned that the person will act immediately, consider hanging up the phone and calling 911, or keep the person on the line and use your cell phone. If possible, you may have someone else call 911 and provide the dispatcher with the person’s name and address, while you stay on the other phone. If the action is not imminent, immediately call the chapter liaison to report the situation.

#### **Intervention Stage**

##### **If the person is in control:**

If you feel confident that the person is in control and able to follow your recommendations, you can suggest considering voluntary hospitalization. You may want to ask if you can contact a family member, friend or his or her doctor. You can also suggest that a family member take him or her to the emergency room.

##### **If the person is not in control:**

If you are concerned that the person does not have control, you will need to alert the police immediately. The more information you can provide the police about the situation, the better. If possible, stay on the line and have someone else near you use another phone to call 911. You could also keep the person on the line and use your cell phone. If you need to hang up, tell the person you are calling for help and will call back immediately.

#### **The Attempt Has Been Made or Is Imminent**

#### **Step 1: STAY CALM**

If you become anxious, you may unwittingly communicate an unwillingness to listen. You will also need to think clearly.

## **Step 2: FIND OUT AS MUCH AS POSSIBLE ABOUT WHAT HAPPENED**

The police will want/need as many details as you can provide:

- Name, address, and telephone number of the person
- Is the door unlocked
- How the attempt was made
- If pills, what kind, how much, what physician, what pharmacy, & how long ago
- If alcohol/drugs, what kind, how much, how long ago
- If gun, where is it now, what kind of gun, is it still loaded
- If knife, rope or razor, where it is and the plans for using it

## **Step 3: CALL THE POLICE**

Your concern at this time should be for helping the person versus worrying about the anger that may result from violating trust. If you believe that interrupting the call will increase the risk of following through with the threat, maintain contact until you are comfortable in calling for help. The longer you stay on the phone, the greater the chance of the person not following through.

## **Step 4: ASK IF THE DOOR IS UNLOCKED**

Explain that you would like to send help and that it would be easier if the door is unlocked when help arrives. If possible, have the person unlock the door while you wait on the phone. In the event that the person loses consciousness, precious time can be saved by having the door unlocked.

## **After the Intervention**

You must not underestimate the toll this experience can have on you. Helping someone through a suicidal time arouses many feelings in the helper—anxiety, sadness, fear, even a touch of despair. Even the most seasoned professionals are shaken when faced with this. These feelings are normal and to be expected. If you find yourself feeling numb, you are defending yourself from your reaction.

It is extremely important to talk about the experience with your chapter staff and sort through how you feel. Carrying those feelings around will pull you down and get in the way of helping someone else.

We must also prepare for the inevitable time when a suicide occurs despite our best intervention. There are times when no matter what was done, the outcome could not have been changed. It is natural to struggle with guilt over not being able to help and feelings of inadequacy and frustration.

Should you experience a suicide in your group, please do not go through it alone. As the family needs help, so do we. Please call your chapter staff so they can help you work through this difficult and emotional experience.

*Adapted from: “Strategies for How to Cope with Distress and Manage a Crisis in Your Group” by Margaret Duthie; American Self-Help Clearinghouse, Denville, NJ; 973/625-9565; and “Collaborative Leadership: Linking National MS Society Self-Help Group Leaders Nationwide”; National Multiple Sclerosis Society, Client Programs Department; January 1999.*

## **Abuse and Neglect**

One of the most difficult things you can learn is that the person you are helping is being abused or being abusive. Abuse can take many forms—physical, emotional, or sexual. Neglect is failure to provide adequate resources for the provision of a minimal level of care. Your chapter has a copy of the Society’s *Guidelines for Addressing Abuse and Neglect*. This document provides information on the definitions of abuse and neglect, the role of the chapter in abuse and neglect, legislative and reporting issues, assessment and intervention strategies, and the emotional impact of abuse and neglect on staff and volunteers who are trying to help clients. For a copy of these guidelines, contact your chapter liaison.

Stress and frustration may lead to abuse and neglect in even the most loving of families. Verbal and physical abuse (by a spouse or partner, by children or parents), as well as neglect, can and do occur regardless of a family’s ethnic or socioeconomic background. The issue may come up in your group meetings or in on-to-one conversations with members of your group. Listen for indicators of abuse or neglect. (Use the *Guidelines for Addressing Abuse and Neglect* as a resource and contact your chapter for help in addressing these challenging situations.)

If you suspect or become aware of an abusive and/or neglectful situation in the home, it is extremely important to discuss your concerns with your chapter and your supervisor. You may not hear about or recognize such issues until later in the relationship with the person. The Society does not expect you to deal directly with abuse or neglect. It is not your role. However, if you suspect abuse and/or neglect, you can play a significant role in helping the person to move into a safer environment, by taking the following steps:

- Call your supervisor and the chapter program coordinator immediately to communicate your suspicions. No more than 24-hours should pass if you suspect that an abuse/neglect situation is happening.
- Debrief with your supervisor as soon as possible. This will help you to maintain good boundaries and emotional health.

It is natural to feel a sense of guilt when reporting suspected abusive and neglectful situations; however, keep in mind that by reporting your suspicions to the chapter and your supervisor, you are not seeking to punish the person who is perpetrating the abuse or neglect. You are, instead, taking the first steps to provide help in a bad situation.

## **EVALUATION AND OUTCOME MEASUREMENTS**

Regular visits by staff and/or key volunteers help promote open, two-way communication.

### **Self-Help Group Outcome Measurement**

Program outcome measurement is vital to the maintenance and improvement of quality for all chapter programs. Assessing the quality and effectiveness of your self-help group is a collaborative process between you, your chapter and group members. Effective measurement of your group's ability to meet the needs of its members requires the ability and willingness to observe, listen and communicate with all of the people involved in the self-help group.

To assess the quality of your self-help group (and the overall self-help group program), you, chapter staff and leadership volunteers will periodically measure the effectiveness of each of these components:

- The chapter's overall self-help group program
- Each individual group
- By the chapter
- By the leader
- By the members
- Each leader's performance

### **Understanding Outcome Measurement**

In order to effectively assess your self-help group and chapter's self-help group program, it is necessary to have clear, specific and measurable objectives. The National Multiple Sclerosis Society has adopted the United Way of America system that makes a distinction between outputs and outcomes when looking at the effectiveness of any program. It is important to go beyond measuring outputs alone or telling what activity occurred.

Outputs include (but are not limited to):

- Number of self-help groups available
- Number of meetings held
- Number of participants served

To determine whether the self-help group program's components are beneficial, we also measure outcomes. Outcomes tell us about the differences a program did or does make in people's lives:

- New knowledge
- Changed attitudes or values
- Modified behavior

Outcomes express the expected impact of the program. They elicit both the successes and the opportunities for growth and change. Outcome indicators are observable and measurable. Examples of methods that your chapter may use to measure outcomes are:

- Pre- and post-surveys of knowledge gained
- Pre- and post-surveys that measure attitudes, feelings, self-confidence
- Written program surveys (e.g. questions in which participants would indicate the degree to which they agree with the statements in relation to their participation in their group)
- Focus groups
- Regularly scheduled visits by staff and/or key volunteers with the goal of creating open, two-way communication

### **Self-Help Group Outcome Measures**

These are the expected outcomes for self-help group leaders and members. As a result of being self-help group leaders, people will:

- Feel helpful to members
- Recognize limits of skill to deal with problems faced by SHG members
- Ask for assistance in working with SHG members
- Receive help in working with SHG members
- Learn skills to be more effective leaders



As a result of participating in a self-help group, members will:

- Know how other people deal with their MS
- Get support from, and give support to, other group members
- Know MS symptoms, research, treatment
- Know how MS can affect self, family and friends
- See the SHG as relevant and useful to self
- Learn adaptive strategies for managing MS symptoms
- Use new adaptive strategy
- Be aware of education and service programs available from chapter
- See chapter programs as relevant and useful
- Participate in other chapter programs
- Know community resources
- Use community resources learned about in self-help group

Most leaders welcome the opportunity to maximize the effectiveness of their group. Leaders can become aware of the group's needs and areas in which to seek new direction through the measurement process. Group leaders and members can use the following suggestions to gather information about their group's status:

- Complete the outcome measurement tools and talk about the results as a group.
- Use the "Is My Group Healthy?" questionnaire (see next page).
- Schedule a specific group meeting to talk about how the group is meeting the needs of members and any changes that may need to be made.
- Inform members that chapter staff, volunteers and self-help group leaders are available and open to direct communication about any aspect of the group.

### **Assessing Your Performance as a Leader**

On a regular basis, you and your chapter liaison will review your work with the self-help group. Your supervisor will remind you of your successes with the group and help you with any challenges you are having. You will have the opportunity to give feedback to your supervisor and ask for help if you need it. Together, you and your liaison will set goals for your role as a group leader and develop a plan to meet those goals.

### **Is My Group Healthy?**

As you look over the statements in the chart on the next page, think about your group as it functions now and decide if the statement is something your group is currently doing or if it is something you would like your group to be doing.

## IS MY GROUP HEALTHY?

	<b>Our group does this pretty well</b>	<b>Our group could use some improvement</b>
People in our group are comfortable talking about themselves.		
Group members talk about how they feel emotionally.		
Members give each other positive feedback.		
Members listen to each other well.		
People learn ways to deal with feelings.		
People are encouraged to help themselves.		
Group members are non-judgmental and welcome new members.		
Group meetings include humor and laughter.		
People feel more informed and empowered when they leave our group.		
Hope is generated within our group.		
Our group functions the way I, as a leader/member, would like.		
I leave our group feeling good about it.		
I feel comfortable in my role as a group leader/facilitator/member.		
Each person talks or participates in someway.		
Our group is positive, yet able to deal with problems.		

1. How does your group handle disruptive behavior or conflict?

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2. What would you like to see changed in the group?

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3. How can group leadership opportunities and responsibilities be shared?

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4. How can the group's communication and relationship with the National MS Society be improved?

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5. Additional comments:

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Here is another survey you might consider using with your group members:

### **GROUP MEMBER EVALUATION**

Answer these questions as honestly and unbiased as possible. Any area for which you checked “No” indicates that it is an area that might need improvement.

<u>Meeting Location</u>	<b>Yes</b>	<b>No</b>
1. Is the meeting location convenient and safe?	_____	_____
2. Is the meeting time consistent and/or convenient?	_____	_____
3. Do you usually begin the meetings on time?	_____	_____
4. Do you usually end your meetings on time?	_____	_____
5. Is the meeting site comfortable and conducive to group discussions?	_____	_____
6. Do you feel comfortable sharing in group?	_____	_____
 <u>Relationships Between Members</u>		
1. Do group members generally trust and respect each other?	_____	_____
2. Is there honest, open communication between members?	_____	_____
3. Do group members avoid cliquish or exclusionary behavior?	_____	_____
4. Do members call each other for support between meetings?	_____	_____
5. Do members practice good active listening skills with each other?	_____	_____
6. Do members let others to finish speaking before jumping in with advice?	_____	_____
7. Are both new and old member's needs taken into account?	_____	_____
 <u>Group Discussion/Process</u>		
1. Is your meeting format flexible when it needs to be?	_____	_____
2. Are new members greeted at the door?	_____	_____
3. Do you have ground rules or group discussion rules?	_____	_____
4. Does each member have an equal amount of time to talk if necessary?	_____	_____
5. Are the meetings positive and constructive?	_____	_____
6. Are group discussions meaningful?	_____	_____
7. Do you feel the self-help group and National MS Society respect your privacy?	_____	_____
8. Do members express caring attitudes towards each other?	_____	_____
9. Were there at least 4 guest speakers this year?	_____	_____

## **EVALUATION OF GROUP LEADER**

	<b>Yes</b>	<b>No</b>
1. Does group leader appear to have a solution-focused attitude?	_____	_____
2. Was the Society disclaimer displayed and/or discussed at all meetings?	_____	_____
3. Did you receive a Society Publications Guide?	_____	_____
4. Did topics covered include Physical Health?	_____	_____
5. Did topics covered include Emotional Health?	_____	_____
6. Did leader discuss Advocacy Days & how to sign up for Advocacy Action Alert?	_____	_____
7. Were programs (such as Walk MS <sup>®</sup> , Bike MS <sup>®</sup> , etc.) discussed?	_____	_____
8. Were you distributed information about chapter activities and events?	_____	_____

### **Member's Needs:**

Write down what you believe to be the top three needs of your group's members. Evaluate whether or not you think each need is being met. If not, write down what obstacles you think might be in the way of having that need met.

Is need being met? (Circle Yes or No. If No, Describe Obstacles)

1. \_\_\_\_\_ Yes    No

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2. \_\_\_\_\_ Yes    No

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3. \_\_\_\_\_ Yes    No

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(continued on next page)

Pretend that you are an outsider (or a newcomer) to your group. Take a close look at the meeting site. Is it comfortable and conducive to group discussion? How do members treat each other, and how well do they listen to each other? Examine the structure of the group. Does it work? Write down what you like about the group, and what areas need improvement. Be very honest. You may use additional paper if needed.

What I Like About The Group:

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What Areas Could Use Improvement?

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How Might We, As a Group, Make Needed Adjustments:

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## APPENDIX A: POSITION SUMMARY



Title: National MS Society Self-Help Group Leader or Co-Leader

Staff Contact: \_\_\_\_\_ Location: \_\_\_\_\_

### Position Summary

Self-help groups in the National MS Society bring people together who share a common life experience (living with MS) for support, education and mutual aid. They share a belief that positive personal change can happen through individual effort with the support of others. Leaders of chapter-affiliated self-help groups are valuable volunteers for the National MS Society and perform an integral role in facilitating this process. Each self-help group is the result of a collaborative partnership between the group and the chapter.

Self-help group leaders and co-leaders, with the assistance and participation of group members, manage the organizational and logistical aspects of group facilitation, by negotiating and dividing tasks among co-leaders and members.

### Responsibilities/Duties:

(These duties are shared with a co-leader or leaders.)

- Serve as liaison to the chapter. Your chapter contact is (NAME) at (PHONE AND E-MAIL)
- Ensure that the group meets in accessible, appropriate meeting space (your chapter can assist in this process).
- Develop meeting times and schedules with group members.
- Ensure that meetings are publicized.
- Together with group members, plan and implement meeting agenda, including inviting guest speakers, using the disclaimer appropriately, planning special programs, organizing activities, procuring videos, tapes, hand-out materials, etc.
- Ensure that follow-up to meetings is provided as needed (e.g. thank you notes).
- Together with group members, open and facilitate group discussion, encourage participation and monitor discussion.

- Ensure that new members are welcomed.
- Arrange, or have another group member arrange, for refreshments.
- Develop and implement a plan to ensure communication with group members between meetings as necessary.
- Assure that the group complies with the National MS Society Self-help Group Standards.

#### Qualifications:

- Willingness to maintain a close working relationship with the chapter and to be a team player.
- Ability to work with minimal supervision from chapter staff.
- Personable, empathetic and welcoming personality.
- Participation in on-going education efforts.
- Willingness to learn about and promote National MS Society programs and events.
- Strength in the areas of communication, group facilitation, organization and management.
- Dedication to the mission of the National MS Society and a desire to make a difference for those living with MS.
- Openness to learning new ideas and approaches to group management strategies.
- Personal relationship with MS.
- Ability to empower and motivate group participants.
- Knowledge of Internet/e-mail technologies and equipment.
- Engagement in or support of chapter-wide activities (e.g. Walk MS<sup>®</sup>, advocacy, etc.).

#### Training/Orientation Provided:

National MS Society chapters provide orientation, on-going support and supervision to self-help group leaders. Initial training and ongoing annual trainings will be marketed and delivered centrally by the Society. In addition, self-help group leaders receive a copy of the National MS Society *Guidelines for Managing Self-Help Groups: A Manual for National MS Society Self-Help Group Leaders*.

#### Performance Evaluation:

Regular evaluation is provided and is based on the accomplishment of the agreed upon objectives and overall job performance. Self-help group leaders will also have the opportunity to give feedback about their own performance, the group's functioning and the support of the chapter. Annual evaluations of both leaders and group performance are recommended. The chapter's self-help group liaison is responsible for facilitating the evaluation process.



- Time Commitment:
- Facilitate monthly 2-hour meetings
- Planning: 1-2 hours/month
- Other logistics and communicating with group members: 1-3 hours/month
- Minimum one-year commitment

Time required will vary if there is shared leadership. Leaders are encouraged to set realistic limits on the time they spend during the month communicating with group members. Shared leadership is highly recommended.

I have read and understand this position description and agree to work to accomplish the responsibilities outlined above. I also agree to work with a team spirit to support the National Multiple Sclerosis Society in accomplishing its mission to mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

Volunteer signature: \_\_\_\_\_ Date: \_\_\_\_\_

Chapter Liaison signature: \_\_\_\_\_ Date: \_\_\_\_\_

## **APPENDIX B:**

### **RELATIONSHIPS WITH PHARMACEUTICAL, MEDICAL DEVICE, RESEARCH OR OTHER COMPANIES**

#### ***Relationships with Pharmaceutical, Medical Device, Research or Other Companies: Frequently Asked Questions***

**There are times when a pharmaceutical company sales representative contacts me, the self-help group leader, directly and offers to arrange for speakers and refreshments for upcoming meetings. Is this an acceptable practice?**

No, it is not. It is the responsibility of individual chapters to explain to their pharmaceutical and medical device companies that representatives are not to directly contact and support the chapter's self-help groups.

Pharmaceutical and medical device sales representatives may find and fund speakers for self-help group meetings, as well as pay for and provide refreshments. The chapter's self-help group liaison is to coordinate these types of requests and should approve of the speaker and proposed content first. When introduced, the speaker must fully disclose that he/she has been paid an honorarium by the pharmaceutical company. If the speaker plans to use handouts provided by the company, the chapter must review the handout in advance. The pharmaceutical or medical device sales representative is not allowed to be present at the meeting.

If a pharmaceutical or medical device company sales representative contacts you directly with a request to bring in a speaker and/or provide food and refreshments for a meeting, please refer the request to your chapter liaison and let the representative know you have done this.

**My chapter has a situation where a pharmaceutical company sales representative attends each meeting of a particular self-help group, providing snacks, befriending members, etc. She is genuinely liked and appreciated by the group members. Is it okay for her to attend the meetings?**

While the sales representative may be a genuinely caring and generous person, her presence at the self-help group is ultimately to promote her company's product. This goes against Society policies, in some cases against the pharmaceutical company's policy, and it may send a message to the group's members that the Society particularly supports this company's product. The chapter liaison should speak to the sales representative and advise her that her attendance is not permitted at meetings in the future. Other employees of pharmaceutical

companies, such as a nurse educator, may attend self-help group meetings but should not promote a particular treatment to the group.

**I receive emails or phone calls from researchers or research companies asking for me to promote recruitment for different MS research studies. Can I share this information with my group members or forward a list of names to them for possible participation?**

No, you should not. You should first contact your chapter liaison to find out if the research study has been vetted and approved by the Society. If it has been, you can share that information with your group members. If it has not, you should not share the information with your group members. You should never release information about your group members to any outside group.

**I have started receiving calls and contact from local medical marijuana dispensaries. Can I have a speaker talk to our group about medical marijuana or cannabis?**

Yes you can, but the same guidelines apply as those we use with other pharmaceutical industry partners. Direct all inquiries to your chapter liaison and your liaison can then share our policies on working with industry partners and the Society's policy on medical marijuana.

To be consistent with our guidelines, if approved by the chapter liaison, only medically qualified personnel (physicians, nurses, pharmacists, etc.) should speak at self-help group meetings and materials or content delivered should be approved beforehand.

Representatives from the medical marijuana industry (such as sales representatives, or staff from the dispensary or grower) are not acceptable speakers. The agenda should only focus on medical use, even in states where recreational use is approved.

## APPENDIX C: RESOURCE MATERIALS

### National MS Society Self-Help Group Meeting Resource Materials

Your first stop in looking for resource materials for meetings, should be the Connection Program Volunteers Resource and Support page on the National MS Society's national website: <http://www.nationalmssociety.org/living-with-multiple-sclerosis/connection-programs/resources-and-support-for-self-help-group-leaders/index.aspx>

The Resource and Support page includes links to recent educational telelearnings for connection program volunteers, as well as the latest self-help group leader meeting-in-a-box toolkits. Many of these toolkits include a video portion, facilitator's guide and associated handouts that you can download right from the website and use with your group members. Hard copies of these materials may also be available by contacting your chapter liaison.

In the toolkit section you will see toolkits available from the Society's North American Education Program (NAEP). The NAEP is an educational program that focuses on topics related to research and/or symptoms. Topics include: "Making Treatment and Lifestyle Decisions," "Hold that Thought! Cognition and MS" and "Pain and Sleep in MS." The NAEP tool kit materials are shipped directly to Society self-help group leaders on an annual basis.

The Resource and Support page also includes links to many of the Society's additional materials. The multimedia library has additional resources for materials and videos that will be helpful for your group. <http://www.nationalmssociety.org/multimedia-library/index.aspx>

## APPENDIX D: MEDIA CONSENT/RELEASE FORM

### Adult Media Consent/Release Form

With respect to the \_\_\_\_\_ (“Event”) to be held on \_\_\_\_\_ with the National Multiple Sclerosis Society, \_\_\_\_\_ chapter, for good and valuable consideration, I hereby agree to participate in the Event. I further agree to release and hold the Society, its directors, officers, employees, agents and chapters harmless from any and all claims and demands arising out of or in connection with my participation in the Event.

I also grant permission to the Society, \_\_\_\_\_ chapter the right to use, reuse, publish and republish my name, voice, likeness, and/or other indicia of identity, in any medium now known or hereafter developed including any print or digital usage for promotional material or publication, alone or in conjunction with other material, without restriction as to changes or alterations, for editorial, educational, promotional and advertising purposes, including without limitation in connection with the solicitation of contributions and the furtherance of the corporate objectives of the Society, and to use biographical and other information about me in conjunction therewith.

In case of an emergency, contact \_\_\_\_\_ at \_\_\_\_\_.

If medically necessary, I hereby authorize appropriate authorities to offer emergency medical treatment.

I have read the foregoing and fully understand the contents thereof.

Date: \_\_\_\_\_

\_\_\_\_\_  
Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Address

\_\_\_\_\_  
Telephone

*SHARE POINT/RISK MANAGEMENT/ADULT MEDIA CONSENT/RELEASE FORM EXHIBIT #10*

## APPENDIX E: DIVERSITY AND INCLUSION STATEMENT

### National MS Society Diversity and Inclusion Statement

MS does not **discriminate** and neither do we: The National Multiple Sclerosis Society embraces and celebrates diversity and inclusion as the core of our organization. We value differences among individuals across multiple dimensions including, but not limited to race, ethnicity, age, gender, sexual orientation, physical ability, religion, spiritual beliefs, and socioeconomic status. We believe that the more we include diverse perspectives and experiences in our work, the better able we are to achieve the organization's ongoing mission of mobilizing people and resources to drive research for a cure and to address the challenges of everyone affected by MS. We create and implement strategies that attract, develop, and retain the expertise, energy, and commitment of a diverse group of talented individuals. By doing so, we boldly and more effectively drive key initiatives to create a world free of MS.