MGFA VISION

A World without MG

THE MGFA MISSION

Is to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy and patient care.

Acknowledgements

Thank you to the American Self-Help Clearinghouse in Denville, New Jersey. Much of the material in this manual is excerpted or modified with permission from articles and tip sheets published by this group.

Thank you to the National MS Society, 733 Third Ave., 3rd Floor New York, NY 10017. Much of the material in this manual is excerpted from National MS Society’s Self-Help Group Manual, printed with permission.
“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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TO BE COMPILED UPON COMPLETION

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Introduction

Leading a Support Group is a deeply rewarding experience, which can be both touching and fun, but it also takes time and energy. Although many Support Group leaders gladly pursue the role for many years, every interested potential leader should carefully consider what is involved in facilitating a Support Group before they work towards getting a group off the ground or take over an existing group from another “retiring” facilitator.

The following background, guidelines and resources lay out key things you as a leader should know, provides ideas and suggestions for running an effective group, presents “tools” to help you carry out the job and gives links to resources which may help you improve your group and your facilitation of it.

Overview and Rationale

There are over 15 million people in more than 500,000 Support Groups throughout the United States. These groups bring together people who share a common life experience for support, education, and mutual aid. Members of Support Groups share a belief that positive personal change happens through individual efforts with the support of others. The benefits of Support Groups to their members include:

- Learning new information and strategies for confronting problems.
- Finding reassurance and support from others with similar life experiences.

To listen is to receive.
--Elie Weisel

Support Group Tools & Resources Section -- Page 1

MGFA, 355 Lexington Avenue, New York, New York 10017, 1-800-541-5454
• Developing personal insights and achieving personal growth.
• The opportunity to be helpful to others.
• Feeling less isolated.
• 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 and personal identification with a social group.

Support Groups are critical to service delivery in the Myasthenia Gravis Foundation of America, Inc. (MGFA). While Support Groups are beneficial to most members, the potential for negative effects and problematic issues also exist. Implementing MGFA’s recommendations and practices described in this manual will minimize the potential for problems, and maximize the many benefits of Support Groups.

**How to Use this Manual & MGFA Support Group Resources**

Begin by taking note of the contents of this manual, including the list of on-line resources that complement it. Make a point of reading every section including MGFA’s *Standards for Support Groups*. As you read each section consider how the contents apply to you and your group and how you might implement them. Note important points and jot down questions. Make copies of the “tools” As you prepare to get started. **COMPLETE THIS SECTION ONCE the REST OF THE MANUAL IS DONE.**
How do Support Groups work?

Support Groups take a variety of approaches. These approaches depend on the needs and interests of the leaders and the members. A Support Group in a spread out rural environment may run quite differently than one set in a dense, urban environment. The needs and interests of groups are likely to differ somewhat based on the characteristics of group members. For instance, are most members retired or still working? Succinctly, groups can differ in many ways such as in terms of...

**Content:** Support Groups can be very educational with regular expert speakers on a variety of topics. In contrast, they can also be like a group of friends sharing their concerns and experiences informally. And, of course, they can be anywhere along this continuum.

**Format:** Support Group members may prefer a “round-table” or a classroom, coffee and Danish on a Saturday morning or an evening in a hospital meeting room with no need for refreshments.

**Frequency:** Support Groups can meet any number of times a year. A monthly schedule is often followed but some groups meet just once a quarter or during only some months of the year.

**Responsibilities:** Leaders can work with members to share responsibilities, such as bringing refreshments, making calls, room set-up, and so forth. In some cases, leaders may be able share responsibilities with a co-leader. Being able to share responsibilities is the ideal approach and should be a goal for your group. More about how, see page ##.

For more practical help in preparing your Support Group start up visit Section ##, where you’ll find check lists, samples and “tools.”
How to start a Support Group.

1. Check – Is there a group in your area?

First, check whether there is already a group in your area. You can find out through the MGFA National Office, neurologists offices, hospitals, and other MG acquaintances. If there is a group, is there a need beyond the existing group? For instance, in a highly populated area, perhaps an additional group, meeting in a different location or on a different schedule, would still attract a good number of participants. Or a group oriented to a younger population, parents of children with MG or another characteristic might be needed. A more specialized group may have fewer potential members and may be harder to get off the ground. But there may be ways to gather people – for instance, many younger people connect through the internet—consider running an on-line group.

2. Call the MGFA at 1-800-541-5454

Once you decide to pursue the idea of creating a Support Group, make the MGFA National Office aware of your plans. Call the National Office at 1-800-541-5454. The National Office can help you get your group started by:
   a. Identifying a list of those who have MG in your area. A list can be generated by having a list of zip codes or the names of towns in your area.
   b. The National Office can email your announcement of a new Support Group to help start up the group.
   c. The National Office can provide you with free informational pamphlets for your Support Group members.
   d. Once you start having meetings, national can enter your members into the data base so that they receive the Foundation Focus newsletter and other MGFA news.

3. Locate Meeting Space

Accessibility. A key standard for all MGFA 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. Besides general issues such as ease of travel and
parking space, accessibility also takes into account those who have difficulty walking; may use a cane or a wheelchair or have breathing difficulties. Every effort should be made to find a location accessible to those with mobility issues.

See the Meeting Place Assessment Sheet on page ## of this guide.

Here are some helpful suggestions for locating a meeting space:

- Private homes are not appropriate meeting locations. Most homes do not meet the 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. So think twice about using a private home for your meetings.

  - Community organizations or agencies such as hospitals, community mental health centers, Red Cross, Salvation Army, Rotary, Lions, Kiwanis Clubs, or senior citizens centers will sometimes provide space free of charge for Support Group meetings.
  - Your local library or daycare centers and schools, banks, municipal town hall or community college are other facilities where Support Group meetings hold meetings.
  - Hospitals 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 Support Groups. Contact the community relations staff person at the “Y”.
  - Places of worship are a common public meeting place for Support Groups. They are usually cooperative in providing space. You and members of your core group can contact your religious leader 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.

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 an accessible restroom(s)
- Has a public telephone available
- Has liability insurance
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. Take a few minutes to touch base with the receptionist, community service staff, building security or maintenance staff, letting them know who you are. 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; 973/989-1122

4. Finding a Team

Although many Support Group Leaders manage their groups very independently, involving others in group leadership is worth the effort. By building a leadership team you give others an opportunity to grow while also creating a strong foundation for the group now and in the future. There are many ways to encourage partnership and responsibility sharing. Here are some ways to encourage others:

- Before you start the process of getting a Support Group off the ground, look for a partner or co-leader. You may be able to find him or her through contacts you already have in the MG community, for instance, through a Walk or your doctor’s office. Perhaps your MG doctor knows of another patient who might be interested and could facilitate an introduction. Another source could be to contact National MGFA and ask them if they could help you find such a person through MGFA social media or by sending an email to other MG patients in your catchment area trying to promote interest. Finally, you might start your Support Group independently but find partners in leadership through the group over time.
- You can also ask the National Office to put you in touch with other existing Support Group leaders who might be able to help you think about what you would like to do and how.
When you start your Support Group, pursue involving members in supporting the group early on. Ask for help with setting out refreshments, assisting those who need help get settled in the meeting room, setting out literature at the start of the meeting and collecting it at the end. Between meetings you might want to ask another member or members to help you make phone calls when a meeting is unexpectedly canceled such as for inclement weather.

Make it clear from the start that the success of the Support Group is a shared responsibility. That means not only participating in discussion but also taking actions that help the group succeed, some of them very practical, like cleaning up the meeting room at the end of the session.

Be generous with praise and thanks for those who contribute. Be encouraging to those who don’t. Some may be afraid to accept a responsibility that will never go away. Some may feel ambivalent about being part of a Support Group. Not everyone is immediately eager to share their struggles, thus they may hold back in further committing themselves to the group. Partnering or sharing responsibilities may be one way to overcome barriers. For instance, rotate responsibilities, such as for bringing refreshments, or use a telephone tree to handle cancelation calls.

Requests for help can be shared with your group members in a friendly, low-key way but also with an expectation of support. A group where no one ever wants to take responsibility for any job is not likely to last if the leader gets sick or moves away. Nonetheless patience may be needed. Sometimes people are skeptical of their participation in a Support Group at first and don’t want to commit for fear of being disappointed. It may take a while to build trust, camaraderie and good examples from others. Even if you don’t have a dozen hands shooting up to help at first, keep trying as you move forward with your group.

5. Get The Word Out

To recruit members to your group you need to “get the word out.” There are many ways to do so. The following are a list of suggestions for publicizing your Support Group. Consider using as many as you can to maximize awareness and expand the pool of possible attendees. Be prepared for questions about your plans, expectations and needs, especially if you don’t have all the details set for your first meeting.
• Ask the National Office to email an announcement for your new group to their database within travel distance of your meeting location.
• Print and distribute a flyer announcing/describing your group
• Place notices on key posting areas: schools, organizations, clubs, shops, hospitals, nursing homes, community bulletin boards, places of worship, libraries, post offices, etc.
• Speak to doctors, nurses, social workers, clergy, administrators, agency directors, media personnel, (i.e., Give copies of your flyers to anyone who might be willing to spread the word)
• Contact your local hospital social services department, community health education department, neurologists, and other doctors who treat people with MG
• Talk to people who have started other Support 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 of places of worship or, request that it be placed in the community section of your local newspaper
• Consider other newsletters (e.g., YMCA)
• Write a press release about your group. Highlight a member who has an interesting story and promote it to a reporter who focuses on human interest stories. A SAMPLE RELEASE CAN BE FOUND ON PAGE ##
• Write a “letter to the editor” of your local newspaper explaining the group’s purpose

Sample Agenda

• Welcome
• Introduce yourself and any co-leaders
• At Meeting #1, and possibly a few other early meetings, explain the purpose of the Support Group and how it works
• Ask those present to introduce themselves briefly
• Begin a discussion based on the contributions of the members OR
• Present your speaker OR
• Present a DVD, Discussion Topic or other focus.
• Moderate discussion
• Wind-up, thanks yous, reminders

SEE Conduct a Good Meeting for More Details and Tips
Types of Speakers
Medical Professionals
Neurologists
Nurses, especially neurology nurses
Pharmacists
Chiropractors
Physiatrists
Urologists
Physical therapists
Occupational therapists
Speech therapists
Licensed clinical social workers
Recreational therapists
Music therapists
Exercise therapists
Massage Therapists
Nutritionists
Pain Management Professionals
Job Counselors
Occupational and physical therapists
Social Workers
Counselors

(it is likely to be printed if you comment in response to a current article or editorial)

- 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


Once you have details of a first meeting set, you can very actively promote interest in attending your inaugural meeting.

6. **Conduct a good meeting**

Meeting preparation.

Develop your thoughts for the meeting. If you are working with a co-leader or helpers, discuss what you plan to do/hope to accomplish. Go to the [Meeting Check Off List](#), Page ### or develop your own.

Look at [Section XX Finding Guest Speakers](#).

Take a look at the [Sample Agenda](#) in the box on page ###. Consider how to adapt it to your needs. Be prepared not only to help make the meeting happen and the discussion flow. Remember that people may be shy, uncomfortable talking to strangers about something personal, or on the other hand, be overly talkative.

Consider the following points:
a. To draw out patients, ask the basics for members of a new group, or new members to an existing group: What is their connection to MG? Are they a patient, caregiver, family, friend? How long have they had MG? Do they have any special questions or issues they would like to bring up to the group today?
b. Remember to try and draw out the shyer participants and moderate the time taken up by those who spend a lot of time talking perhaps preventing others from participating. For instance, try phrases such as these:

   i. Interrupt the lengthy speaker even if you can’t find a little break in their speech with something like, “Thank you, --name--, we appreciate your [story, insights, suggestions], but we need to let others share their thoughts considering our limited time.” Or, try something similar.

   ii. For those who are shyer, perhaps you can gently ask them if they have a comment on the topic of conversation. “--Name—would you like to comment or share on our --topic--?”

c. If time allows and this leads to discussion, moderate and guide it as needed to maximize its productivity.

   i. Speak briefly about MGFA, MGFA literature, website and Facebook page.

   ii. Introduce your speaker, or MGFA or other resources, for instance, play an MGFA podcast, webinar or annual conference DVD.

   iii. What questions do participants have for the speaker?

   iv. At the close of the presentation, lead a discussion. What were some of the most important, meaningful or memorable points?

d. Wind up your meeting with

   i. A summary statement about what was learned or shared during the meeting.

   ii. Thanks for the speaker and others who made significant contributions.

   iii. Reminder of the date and time of the next meeting and any other group business such as a special event.

   iv. Reminders such as local MG Walks, special Support Group events or resources or events in your community.
Topics for Meetings

What is your group interested in learning about or discussing?

Think about what your group members are interested in and develop meeting plans accordingly. You could conduct a “formal survey” or you could just look for ideas through a conversation among the group.

Content ideas:

- Get to know one another better – each member speaks about their major concerns about MG, or each answers a question or talks on a topic of concern such as managing relationships through the prism of MG.
- Medications – issues and questions – include a neurologist or pharmacist as an expert. Avoid misinformation on this important topic.
- The latest research on MG.
- Work and MG – Strategies for managing work, communicating with your boss and co-workers about MG, finding a new job—what to share or not share about MG.
- Talking with your friends, family and co-workers about MG.
- Assistive devices to aid with everyday tasks.
- Arranging your life to minimize MG’s issues.
- Healthful living – exercise and nutrition – how to maximize your health through best dietary and exercise practices.
- Making a difference for MG – participating in walks, advocacy, sharing your story...
Tips for Your First Meeting

At the first meeting, underscore the fact that the group is a Support Group that is affiliated with the MGFA. Invite other MGFA volunteers in your area to attend and perhaps say a few words about MGFA. Here are some additional tips for the first meeting:

- **Discuss and reach a consensus with your leadership group** about what the general purpose, goals, and membership of the group might be before your first public meeting. Present those ideas at the first 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.

- **State the group’s possible purpose and goals** at the first meeting. Get new members comments and feedback. 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.

- **Give all attendees 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.

- **Discuss a possible name for the group.** 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.).

- **Avoid dealing with organizational issues** for the first meeting these might be more easily taken up at subsequent meetings.

- **Review MGFA’s Standards for Support Groups.** 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 MGFA. See page ##.

- **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.

- **Develop a plan for your group’s leadership structure** over the course of the first several meetings. There are different models of structure and leadership used by groups ranging from highly organized groups with 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 MGFA Support Group is to initiate and facilitate the mutual aid process that occurs when members share their own insights and skills in living with MG.

- **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; 973/989-1122.*

**SUPPORT GROUP MEETING DISCLAIMER**

The information presented at this meeting does not necessarily reflect the views or official position of Myasthenia Gravis Foundation of America, Inc., nor carry the endorsement or support of MGFA.

- For specific medical advice, contact your physician.
- For the opinion of the MGFA’s Medical Scientific Advisory Board or Nurses Advisory Board on any therapy, treatment, or product, please contact MGFA at 1-800-541-5454 or visit the MGFA website at [www.myasthenia.org](http://www.myasthenia.org).
Finding Guest Speakers

Follow MGFA Standards for Support Groups regarding minimizing risk to group members and the national MGFA when selecting speakers and program topics. Use the MGFA Support Group Disclaimer and make every effort to offer unbiased, well-rounded programs. See the Box on Page ## for ideas on types of speakers.

- 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, lawyer, or another) 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.

- 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, 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 MGFA Standards for Support Groups (see page ##) regarding minimizing risk to group members when exploring this option. 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 MGFA Support 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. tape of a radio interview show (25 minutes long or less), conference presentation, portion of a TV program, etc.). Or start a DVD library of your own, by asking some of your “live” guests if you may record their presentation for your group’s lending library collection.

Adapted from: “Finding Guest Speakers for Your Group”; American Self-Help Clearinghouse, Denville, NJ; 973/989-1122.
Sample Group “guidelines”

You may find it helpful to develop a set of group guidelines that members will aspire to and adhere to. Guidelines can be added to or changed as the needs and the experience of the group and its members develop over time. The Guidelines are a way to strengthen the group and make it function more smoothly and more maturely. Here are examples of assorted group guidelines from FAIR (Family And Individual Reliance, a program of the Texas Mental Health Association) and from the WE CARE (divorced and separated) group of the Wilder Foundation in St. Paul, Minnesota:

• We are a group of people with a common bond sharing our troubles, understanding and wisdom.
• We listen, explore options, and express our feelings. We do not prescribe, diagnose, judge, or give advice . . . we suggest.
• We know that what we share is confidential and that we have the right to remain anonymous if we choose.
• We have the right to take part in any discussion or not. It is important that we actively listen when someone is talking and avoid having side conversations.
• We encourage “I” statements, so that everyone speaks in the first person.
• Having benefited from the help of others, we recognize the need for offering our help to others in Support Groups.
• We are here to share our own feelings and experiences. Respect and maintain the confidentiality of the group.
• Avoid interrupting. If we do break in, return the conversation to the person who was speaking.
• Side conversations are not allowed.
• We each share the responsibility for making the group work.
• We each have the opportunity for equal airtime or the right to remain silent.
• We try not to discuss persons who are not present.
• We have the right to ask questions and the right to refuse to answer.
• We encourage members to share their strengths, skills, insights, successes (small or large), and their hopes.
Working with Speakers from For-Profit Companies

MGFA’s Standards for Support Groups state that Support Groups have the right to choose discussion topics and speakers for meetings, and the responsibility to minimize risk to group members and to the national MGFA. One of the methods of minimizing risk is to use the Support Group Meeting Disclaimer at every meeting.

MGFA’s Standards for Support Groups has guidelines for working with for-profit companies that help to ensure that the information we provide is accurate and unbiased. Support Groups follow those policies. To help you understand these policies, here is a summary of the guidelines that pertain to Support Groups. If you have additional questions, contact the National Office of the MGFA.

- No staff person, volunteer, speaker, self-help group leader, or member shall utilize a Support Group for personal gain.

- Give product information from a pharmaceutical company only as a supplement to MGFA materials. Prior to your meeting, ask your national MGFA to send you current literature about the topic.

- Lists of Support 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 MGFA.

- Support Groups need to provide balanced, accurate information to its members. Support Groups invite a variety of speakers to their groups. To ensure that information given in your Support Group is accurate and balanced, invite speakers with differing
opinions to attend your group, ask for input from your national MGFA about a speaker, and encourage Support Group members to ask questions of all speakers.

Meeting Ideas

Support 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 MG.

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 MG 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.

Participate in MGFA’s June Myasthenia Gravis Awareness Month

MGFA celebrates “June Awareness” each year as a way to make the public and medical community more aware of MG. A kit is sent to all Support Groups and other volunteer leaders to help them carry out a variety of activities around the observance. Look for your kit by March or before.
• 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 MG.
• Introduce the MGFA’s myMG application an innovative mobile application (or “app”) that gives people who have Myasthenia Gravis (MG) a new tool that enables them to track their MG. [“My MG” is a software application designed to run on Smartphones, tablet computers and other mobile devices for use in daily life.] http://mymg.myasthenia.org/home -- click on the Banner when it shows myMG.

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.
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.

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 Support Group.
- Attend an MGFA educational program together.

Community Involvement
- Join in for MGFA’s June is Myasthenia Gravis Awareness Month. Look for the distribution of the annual PR Kit in February/March each year, or ask for a copy of last year’s to get a head start on your own planning.
- Participate in the National Organization for Rare Diseases’s (NORD) Rare Disease Day which takes place the last day in February each year. Visit the NORD website for ideas and resources to participate. [http://rarediseases.org/](http://rarediseases.org/)
- Participate in the MGFA’s *MG Registry* – this is a major way that each MG Patient can contribute to a better understanding of the disease and support research.
- Volunteer together in your community.
- Take valentines to a nursing home.
- Write letters to your congressional representative or local officials together.
- Write to local businesses about accessibility.
The Low Country Carolinas Support Group sharing their support of Rare Disease Day 2015.

**Recreational**
- Attend an aquatics program.
- 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.
- Have a holiday gift exchange.
- Hold a potluck dinner.

**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:

- *Circulate a list of selected members’ phone numbers* after they give permission. Members can call one another in between meetings for conversation, information and support. A few groups set a time limit to individual calls (e.g. that a phone call shouldn’t go longer than 15 minutes).
- *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 a correspondence circle, wherein one member starts it by writing a letter telling their experience, indicating what they have learned about coping with the problems, and what they seek to learn. The letter goes to the next member in the circle (circles are often 6 to 8 members), who
adds his or her own experience and insights to the letter, and then can also comment on the earlier letter(s). Letters are kept in a folder and move on, circulating a second or sometimes third time around as an added set(s) of letters is developed.

- Send a meeting reminder and/or keep your national MGFA informed about your group’s schedule so it can be included on the MGFA website.
- 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).
- Plan social activities. e.g. potlucks, holiday parties, picnics, or go out for entertainment together.
- Participate in on-line computer exchanges. Increasingly, members of local face-to-face groups can and do participate in on-line mutual help groups through message boards, e-mail discussion groups, newsgroups, and issue-specific chat rooms that are, for the most part, available 24 hours a day. The MGFA website can be reached at www.myasthenia.org.


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].”

• Share good news gathered from outside the group related to myasthenia gravis (e.g. new research results, helpful magazine articles, news from other organizations and agencies that address disability issues, etc.).

• To help keep the discussion upbeat, encourage members to share their strengths, skills, insights, successes (however small), and their hopes.

• 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” (e.g. 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).


Ways to Structure Your Group Meetings
Meeting formats for MGFA Support Groups range from loosely structured discussion groups to more formally structured meetings. The following activities are common to many Support 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. In many Support Groups 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. Tapes, 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.
  
  o Round. Ask a question or ask participants to complete a statement and go around the group as each person responds, giving everyone a chance.
  
  o Brainstorming. Ideas are shared in a spontaneous way. Creative thinking is encouraged by not judging any particular idea.
  
  o 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.


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

1) Who has been most/least supportive to me in helping me deal with my MG? What have they done or said that has helped or not helped me? When someone is not supportive or helpful, how have I managed?

2) What were my family and friends’ reactions to the news that I had MG? How did it differ from what I expected, from what I wanted? Have I been able to shape people’s reactions to me? How?

3) How do I maintain my relationship with my spouse when I need to give or receive physical care?

4) Dealing with family and friends who hear about a therapy or treatment and want me to take it.

5) Who is the easiest person to talk to about MG? Why? Who is the hardest person to talk to about MG? Why?

6) How do people react to me when they learn that I have MG?

7) What do children need to know about MG?
8) Dealing with my feelings of inadequacy or guilt as a parent with physical limitations.

9) Dealing with family and friends who don’t understand my fluctuating fatigue.

10) Maintaining a social relationship with my friends when I have physical limitations.

11) Dealing with family and friend’s expectations when I don’t look “sick.”

12) Has MG affected my family’s communication?

13) Communicating my feelings and needs.

14) Helping my friends and family to understand.

**Taking Care of Yourself**

1) Asking for help.

2) Saying “no” without guilt.

3) How do I maintain my independence?

4) Dealing with bowel and bladder difficulties.

5) What challenges related specifically to MG have I faced and overcome?

6) What challenges have I not handled as well and why not?

7) MG and sexuality.

8) Handling exacerbations. Dealing with the unpredictability of MG.

9) How do I promote “wellness” in all areas of my life?

**Personal Feelings**

1) In the past, what did I think about people who had a disability or chronic illness?

2) Dealing with differences in disability among Support Group members.

3) How did I feel when I was first told that I (or another family member) had MG?

4) How do I deal with any stigma I have experienced due to my illness?

5) 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?

1) To what degree have I learned to accept or come to terms with the illness, and what has helped me to do this?
2) Traveling and vacationing with MG.
3) Aids or little tricks that I have found helpful in my everyday life.
4) Considering using assistive devices.
5) Dealing with “invisible disability.”

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

Physician/Professional Relationships
1) Do I get angry with my doctor? About what? Do I say or do anything about that?
2) What are my relationships with my doctor, neurologists, and other medical professionals?
3) 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?
4) How has my doctor made me feel especially good or bad?

Employment
1) How has MG changed my work situation?
2) Should I disclose my MG at work?
3) Asking for reasonable accommodations at work.
4) Working around fatigue.

WEBSITE RESOURCES

For more help in managing your group and understanding the challenges that can arise visit the MGFA website (link) to learn more on these topics:

- Handling Challenging Situations in the Group
- Active Listening
- How to Minimize Distress in Your Group
- Group Problem-Solving
- People Who Disrupt the Group
- Encouraging Expected Behavior
- Dealing with Anger in the Group
- Handling a Crisis Situation
- Assessing an Emotional Crisis
- Preparing to Respond to a Group Member Expressing Suicidal Thoughts or Feelings
- MG and the Emotions
- Common Emotional Reactions to the Disease
- Emotional Changes Caused by the Disease
- Clinical Depression—A Reaction to the Disease and/or Part of the Disease
- Responding to a Group Member’s Possible Risk of Suicide
- How to Prepare for Crisis Situations
- After the Intervention
- Abuse and Neglect
- Support Group Evaluation
- Resources (list of websites and books)
Standards for MGFA Support Groups

Introduction:

These standards reflect the Myasthenia Gravis Foundation of America (MGFA) mission to support people with MG through research, education, community programs and advocacy. These standards are models of practice for all MGFA Support Groups. MGFA recognizes that each group is unique and dynamic, depending on its members and changing circumstances. MGFA also seeks to ensure that all participants have access to a high level of commitment, information, and assistance; with these goals in mind we urge each group to comply with one set of standards that reflect best practices and conformance to MGFA policy.

These standards represent measurable criteria that should be used to evaluate the effectiveness of Support Group programs and their facilitators. The standards outline MGFA’s role as well as expectations for facilitators and Support Group participants. The standards address risk issues for MGFA, its staff, and volunteers.

The standards that follow are based upon established guiding principles and practices from both within MGFA and from outside the organization. They are intended to facilitate practices that achieve mutual benefit to MGFA and individuals affected by MG. To fulfill this intent, Support Group facilitators share responsibility for upholding these standards and must be willing to commit to:

- Provide accurate and appropriate information;
- Empower Support Group participants;
- Represent the MGFA positively;
- Provide feedback to the MGFA;
- Adhere to all MGFA guidelines; and
- Support the Support Group process, goals and participants.

Support Group participants also share some responsibility in upholding the standards.
MGFA Support Group Standards:

1. Individuals who serve as Support Group facilitators possess skills and attributes to organize and lead a Support Group effectively.

These skills and attributes include:
   a. Willingness to maintain a close working relationship with the National Office and to be a team player;
   b. Ability to work collaboratively and with minimal supervision;
   c. Personality that is empathetic, personable, and welcoming;
   d. Commitment to participate in on-going training;
   e. Willingness to learn about and promote MGFA programs and events;
   f. Strength in communication, group facilitation, and organization and management;
   g. Dedication to the mission of MGFA;
   h. Desire to make a difference for those living with MG;
   i. Openness to exploring new ideas and learning new approaches to group management strategies;
   j. Personal experience with or knowledge of MG;
   k. Ability to empower and motivate group participants;
   l. Knowledge of internet/e-mail technologies and equipment;
   m. Engagement in, or support of, community activities; and
   n. Ability to maintain objectivity regardless of personal opinions or needs.

2. MGFA describes the roles and expectations of Support Group facilitators, and facilitators work within the parameters of the descriptions.

   It is critical for the success of Support Groups that facilitators understand what MGFA expects of them. Facilitators need to know tasks they are expected to perform (responsibility), the parameters within which they work (authority), goals oriented toward results (accountability), and how they will know if they have achieved the desired results (measurement).
3. **Support Group facilitators and participants maintain confidentiality.**

Maintenance of confidentiality means that any identification or personal information revealed in a group meeting is not revealed outside the MGFA; identifiable information, photos, or videos are not disclosed without individuals’ written authorization; and group participant lists are not distributed outside the Support Group.

4. **Support Groups meet in accessible places of public accommodation.**

It is a MGFA standard to conduct official functions only in public accommodations that meet American with Disabilities Act (ADA) accessibility standards.

- Meetings must be held in public locations that meet ADA accessibility standards. These accessibility standards are found at http://www.access-board.gov/adaag/html/adaag.htm.
- Support Group meetings must 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.

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Support Groups abide by the non-discrimination policies of MGFA and are open to new members.

Support Groups accept new members into their groups on an on-going basis. **MGFA Support Groups accept people who are part of the MG Community (patients, family, friends, professionals). Support Groups do not discriminate based on faith, lifestyle, race, ethnicity or national origin, gender, disability or**

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Pacific Northwest Support Group leaders Kathie Bibeau and husband, Ray Bibeau, 2014 Volunteers of the Year.
Support Groups should be welcoming and inclusive. Practices that may make some members uncomfortable such as prayers representative of one religion over another or criticizing members for their lifestyle or other protected characteristics or background are discouraged.

Although places of worship can be a convenient place to meet, more neutral locations are preferred. If a Support Group meets in a place of worship, it should be very clear and frequently repeated that all potential members are welcome.

Support Groups may have a special focus (e.g. a group for working women, a caregivers group, a group for people “mildly affected”). However, a group may not, for example, have a “no wheelchairs allowed” policy, even if their focus is dealing with invisible symptoms.

5. Support Group facilitators do not give medical advice.

Facilitators do not offer medical advice, even if they are health professionals or by trade are involved in the health care community. Facilitators and members may share information on personal experiences, treatments, etc., but refrain from giving personal interpretations or advice, sharing medication or offering recommendations.

6. Support Group facilitators distribute only MGFA approved literature.

7. Support Groups uphold MGFA policies affirming life.¹

The National MGFA will provide Support Groups with training and materials that describe the MGFA positions on suicide and assisted-suicide, abuse, and neglect. Group facilitators must alert national staff if they perceive a potential danger for individuals doing harm to ¹Sections highlighted in yellow need decisions concerning MGFA policies, possible new “Unification” organizational changes and their impact.
themselves or others. This standard includes alerting national staff if abuse or neglect is suspected and reporting imminent threats to life to appropriate social service agencies or law enforcement immediately or as urgency dictates and local reporting laws require and to national MGFA. [NOTE: 10/1/15 -- MGFA National Office will be developing these resources.]


8. Support Groups comply with MGFA fiscal policies.

- MGFA recognizes that in managing a Support Group, facilitators may incur out-of-pocket expenditures such as those for postage for meeting reminders, meeting room costs, program presentation equipment, and/or refreshments. In order to receive reimbursement for basic expenses receipts are required.
- But we do urge Support Groups to keep their expenses low. Seek out a free meeting room; collect support for refreshments from the group if possible (a donations jar is very low key). We also urge Support Group Leaders to make a point of encouraging members to support their group’s activities such as contributing to a refreshments kitty. Mutual support of the group strengthens member commitment.
- Support Groups affiliated with MGFA cannot open any type of bank account in the name of the MGFA or under any other name or circumstance.
- According to 501(c)3 of the Internal Revenue Service (IRS) code, any monies received by a Support Group must go directly to the national MGFA. MGFA Support Groups cannot raise funds in the name of the MGFA that it intends to restrict to its own use, nor can a MGFA Support Group state or imply that a contribution to such a restricted purpose is tax-deductible.

MGFA is exempt from income tax under section 501(c)3 of the IRS code. This designation allows donors to deduct any contributions to Support Groups (or national MGFA) from their income tax return in accordance with current law. The 501(c)3 designation does not extend to Support Groups so any monies collected by MGFA Support Groups must be collected on behalf of the national organization. This procedure allows the donor to take the tax deduction allowed by law.
If a donor wants to restrict a contribution to support a particular Support Group, this intent must be in writing and monies directed to the National Office where it is held as a temporarily restricted asset. National has the responsibility to decide whether or not it is possible to accept any restricted donation. MGFA policies preclude any staff person or volunteer from asking for restricted gifts of less than $500.00.

9. **Participation in Support Groups is free of charge.**

If a Support Group asks members for contributions to defray minor expenses, these contributions must be voluntary. A group may, if members agree, have meetings in conjunction with a meal or activity in which each member covers his/her own expenses.

10. **A Support Group may deny participation to individuals whose behavior is disruptive to the group process.**

The Support Group has the right to deny admittance to any person who persistently exhibits behaviors that are disruptive to group meetings, harasses other members, or in other ways presents a risk to group members or to the meeting process.

Ideally, this difficult decision will be made only after reasonable attempts have been made to address the inappropriate behaviors through discussions with the individual outside of the group environment. The Support Group leader may call the National Office to discuss this challenge with the aim of resolving the difficulties he or she is facing. If these attempts prove unsuccessful, the group facilitator will develop a plan of action. Part of which will be contact with the National Office to discuss the plan. Appropriate alternative community services will be sought for the individual.

11. **Support Group members have the right to choose discussion topics and speakers for meetings, and facilitators have the responsibility to minimize risk to group members.**

Group participants plan meetings and choose speakers and discussion topics. Meeting agendas must not conflict with MGFA’s mission, policies or Code of Conduct. For example, in accordance with MGFA policies, no staff person or volunteer may utilize a Support Group
for personal gain. As a second example, our policies would be violated by allowing group members to participate in bee sting “therapy” following a discussion on this topic. In the event that the agendas of a particular Support Group regularly and persistently conflict with the mission and/or policies of MGFA, and attempts at resolution have failed, the MGFA 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 MGFA programs.

Attendance Records must be maintained for each meeting. The sign-in sheet, including name, address, telephone number and email address must include the following disclaimer:

### SUPPORT GROUP MEETING DISCLAIMER

The information presented at this meeting does not necessarily reflect the views or official position of Myasthenia Gravis Foundation of America, Inc., nor carry the endorsement or support of MGFA.

- For specific medical advice, contact your physician.
- For the opinion of the MGFA’s Medical Scientific Advisory Board or Nurses Advisory Board on any therapy, treatment, or product, please contact MGFA at 1-800-541-5454 or visit the MGFA web site at [www.myasthenia.org](http://www.myasthenia.org).

12. **Support Groups share responsibility to ensure that group affiliations with other organizations are beneficial to MGFA and in accordance with MGFA policies.**

Support Groups are encouraged to utilize community resources through formal or informal affiliations, provided that attention has been given to the focus and integrity of the other organization and the outcomes that will be achieved through the association. Affiliations are forged only when doing so will strengthen, not interfere with, fulfillment of the MGFA mission and not result in exploitation of MGFA or its members. Other organizations may...
have different requirements and standards. Groups must adhere to those of MGFA to have dual affiliation.

13. Relationships with pharmaceutical, medical device, research or other companies are managed through the National Office.

Individual Support Group leaders have the responsibility to explain to pharmaceutical representatives that they cannot provide support directly to the Support Group. National MGFA will advise Support Group facilitators in this policy.

Such companies may find and fund speakers for Support Group meetings, however, the Support Group leader must review and approve the speaker, content and any handouts. The speaker’s connection to the company must be fully disclosed to the Support Group members. If the Support Group leader is in doubt contact the national office at 800-541-5454. It needs to be clear that the MGFA and the Support Group does not support this company or their product over any other company or product. The role of a company-supported speaker is to provide information and education, not to sell a produce or service.


Refer to Standard 13 above. Only medically qualified personnel such as physicians, nurses and pharmacists should speak about the medical uses of marijuana. Representatives from the medical marijuana industry, for instance, a sales rep, grower or dispensary personnel are not appropriate.

15. Promotion of research trials to Support Group members.

MGFA promotes research vetted through its Medical/Scientific Advisory Board. Announcements of research trials are announced on the MGFA website www.myasthenia.org. It is very appropriate to educate members.

Standards 13 to 15 adapted from the National Multiple Sclerosis Society.
about the importance of research in general and what is entailed in participating in a trial. Members may be referred to the myasthenia.org website and to www.ClinicalTrials.gov where they can find studies that have been listed through the National Institutes of Health (NIH).

14. **MGFA policy allows for groups to have a specific faith based focus, as long as a more generic group is offered within reasonable proximity.**

Faith is an important coping mechanism for many people living with MG. However, MGFA is a secular organization, welcoming those of every faith, and those who espouse none. In general, MGFA asks that Support 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 standard and guideline pertaining to open membership.

If a group chooses to have a specific faith-oriented focus, then the Support Group must promote that focus clearly in any promotional materials for the group and inform any potential members of the nature of the group. Additionally, National will seek to set up a non-faith-oriented Support Group meeting in close proximity to one that is faith-oriented.

15. **Support Group facilitators are advised of and recognize the risk of transporting group members to and from group meetings.**

Transportation of participants to or from Support Group meetings is not within the scope of the duties or responsibilities of Support Group facilitators. If a Support Group facilitator decides to act outside the scope of their duties and responsibilities by providing such transportation in their own vehicle, he or she should understand that he or she could be held liable for any damages and injuries incurred by their passengers in the event of an accident. Therefore, before providing such transportation, Support Group facilitators should ensure that their personal liability insurance is sufficient and would provide coverage for any such damages and injuries.
“Each morning when I open my eyes, I say to myself, “I, not events, have the power to make me happy or unhappy today. I can choose which it shall be. Yesterday is dead. Tomorrow hasn’t arrived yet. I have just one day, today, and I’m going to be happy in it.”

Groucho Marx