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Overview

Support groups provide a supportive environment in which people with similar needs can share information, learn from others’ experiences and build a sense of community. Support groups within the Myasthenia Gravis Foundation of America’s network of chapters offer participants a forum through which they can share their struggles and frustrations related to Myasthenia Gravis (MG) and engage in a dialogue with others who share similar experiences with this disease. These groups can provide people diagnosed with MG with a feeling that they are not alone in their struggle with chronic illness. Help is offered on the basis of the experiences of members rather than professional expertise. Having the opportunity to share experiences, express feelings and reflect on how to cope with MG can help group members overcome feelings of isolation, frustration and anger and promote a better understanding of the disorder and its implications.

What are some types of support groups?

Through support groups, participants can receive emotional support, practical information, education and advocacy. Groups can focus on education, social opportunities and emotional support. Often groups can serve several purposes, with one being dominant at any given time. A key first step in starting a group is deciding the primary purpose of the group and developing a format to achieve that purpose.

Educational

Some groups exist primarily to provide practical information about Myasthenia Gravis and other health-related topics. These groups often invite experts to speak about their specialty areas. Many support groups regularly offer a guest speaker and share current literature or resources. Guest speakers can include:

- medical professionals
- counselors
- clergy
- pharmacists
- neurologists
- chiropractors
- massage therapists
- nutritionists
- pain management clinic staff
- job counselors
- occupational and physical therapists
- and other specialists

Speakers will generally volunteer their time. Encourage them to leave information, brochures and business cards on an information table, if desired, for members’ reference. The coordinator should confirm speakers prior to the meeting and send a thank you note following the event.
Social
These groups serve as a social opportunity for participants. Social groups are more informal and are organized for members to spend time together, generally engaging in a group activity such as a group sport, eating out, or attending a community event. Discussion is generally not facilitated in this type of group.

Emotional Support and Personal Growth
This type of group offers emotional support for people who suffer from a specific illness or disorder. In these groups, members are encouraged to express their feelings and share ideas for coping with their common issue. Discussion in emotional support groups is often facilitated by a professional therapist or mental health practitioner, but can be facilitated by volunteers as well, provided that the leader clearly states that he or she is not a mental health professional and that the group is not a substitute for clinical therapy.

How do I start a support group?

1. First, determine whether a group exists in your area. If none exists, designate a coordinator who is willing to organize group meeting dates, reserve meeting space, obtain guest speakers, collect informational resources, send notifications of meeting details and facilitate the meetings. Some of these tasks may eventually be shared with other group members. Consider a visit to an existing support group (regardless of the topic) to see how other groups operate.

2. Establish who your audience will be. Think about the potential members for this group: what are their ages? Are they MG patients or family members? Are there any special accommodations needed, such as wheelchair access, interpreters or transportation?

3. Estimate the size of the group. In order to determine the best location for the meeting, it is important to have an idea of how many people may be attending. Estimating the number of potential attendees will also help determine the quantity of refreshments and the number of chairs needed. Consider requesting an RSVP for each meeting.

4. Select a meeting site. Choose a site that is centrally located and accessible to participants. Keep in mind any special accommodation needs of your group. Select a site that is familiar to participants, such as a hospital, public library, community center or local nonprofit organization. Be sure to reserve the room and let building staff (such as a receptionist or maintenance staff) know that you are there. Use signage to direct people to the appropriate entrance and meeting room.

5. Decide whether there will be a charge for participation in the group. Do participants need to be dues-paying chapter members? Will you request a free-will donation? Does your chapter have funds to help with expenses such as mailing costs or printing?

6. Publicize your group, using a number of methods to promote attendance:
   a. Insert a flyer in your chapter's newsletter
   b. Request a listing of your group in your local newspaper community section
   c. Drop off copies of your flyer to local hospitals and clinics, libraries, community centers and other public places
d. Ask your local United Way or other community organization whether they maintain a listing of support groups in the community and request that the group be listed.
e. Send postcards, email notices or make phone calls to remind regular attendees of the meeting.
f. Write a press release and submit it to several area newspapers, television and radio stations. Consider featuring the personal story of one of your members. Send the release directly to a writer who focuses on human interest stories. A sample release is found in Appendix F.

**How should the meetings be structured?**

1. Determine whether your group will be an open group or a closed group. In other words, will new members be allowed to join at any time, or must members all begin together when the group starts? Can family members, professionals, people diagnosed with other disorders and others participate or is the group restricted to people with Myasthenia Gravis (and closely related disorders) only?

2. Decide whether the coordinator will facilitate discussions or group members will take turns facilitating. If the group will rotate its facilitator, a schedule should be determined in advance, to ensure that people are prepared to lead the discussion and that an experienced participant is chosen.

3. The support group coordinator’s responsibilities are to:
   
   a) Notify group members of the time and location for each meeting. It is helpful to set a consistent schedule for meetings, such as the 3rd Tuesday of each month from 7-8:30 PM, and a regular meeting place.

   b) Greet members at the door, or assign another member to do so.

   c) Ensure that everyone fills in the sign-in sheet at each meeting. Maintain a list of members with name, address, email and phone number. The list can be distributed within the group, with the understanding that the information is not to be shared with anyone outside the group (e.g. salespeople, other organizations).

   d) Keep emergency contact information for each attendee (name, address and phone number of close relative or friend) available at each meeting in case of emergency.

   e) Have information available at each meeting from your chapter and the national office, such as copies of a recent newsletter, pamphlets, information on upcoming events, order forms for merchandise and other materials as deemed appropriate.

4. Delegate some responsibilities if appropriate. Delegating can instill ownership in group members. Some suggestions include:

   a) Program Planner — arranges for speakers for each meeting or decides the discussion topic

   b) Refreshments Coordinator — responsible for food and drink arrangements

   c) Communications Coordinator — publicizes each event

   d) Membership Coordinator — keeps an ongoing and current list of members names, addresses, email addresses and telephone numbers; and reminds members of each meeting
5. Start promptly and end promptly. The facilitator can encourage people to socialize before or after the group meeting to ensure that the meeting is kept within the publicized time frame.

6. Arrange chairs in a circle so people can make eye contact with everyone in the room.

7. Eliminate distractions where possible. Keep the door to your meeting room closed to assure privacy and preserve confidentiality for the members. Schedule a break midway through the meeting to minimize disruptions.

8. Begin and end the meeting on a positive note. Suggestions include: asking group members to share the high point of their week or month, reading an inspirational quote, leading a breathing/relaxation exercise or sharing local chapter news and national foundation information.

**What are Some Guidelines for Meetings?**

1. A confidentiality agreement should be maintained with each participant. A sample form is included in Appendix D. Discuss with each participant the importance of maintaining confidentiality, while cautioning them to exert discretion about the level of disclosure they are comfortable with. Share with your group that support groups enjoy no legal privilege of confidentiality.

   Confidentiality is an important feature of a safe group; however, the facilitator is required by law to report certain issues to appropriate authorities. These include:
   a. if a group member threatens to do harm to self or others.
   b. if a group member is (or has been) involved in harm to a child or elderly person.

   If a group member learns of these threats or behaviors, the facilitator should be informed immediately and a report should be made to the appropriate state agency.

2. Introductions should take place at the beginning of each meeting. Name tags can be helpful for learning names. People who arrive late should introduce themselves when they arrive. During introductions, it may be helpful for people to share with the group such things as: How long have participants been diagnosed with MG? What are their symptoms? Who is their doctor? How much knowledge do they have about MG? What do they expect to gain from participating in this group?

3. A support group cannot substitute for therapy. Therefore, advice-giving or problem-solving are to be avoided. Encourage participants to share their own experiences, while allowing others to do the same. It is best to leave complex problems and situations to professional therapists and focus your group on practical support issues. If a participant’s emotional needs are not being met through the group, the coordinator should consider making a referral to an appropriate mental health professional.

   Some clues to help identify a member who may need a referral include:
   a. Member cries at the same point of their story over several meetings.
   b. Member continues to decline to share his or her story after several meetings.
   c. Overt anxiety escalates over time.
   d. New fears are apparent that interfere with regular daily activities.
e. Member acknowledges loss of sleep, loss of appetite or low self-esteem.

f. Member speaks of suicide (this should always be treated as an emergency, even if the member seems to be joking)

g. Use of drugs or alcohol appears to increase.

4. If emotional support is the primary focus of the group, the size of the group should remain under 12 participants. If too many people attend the group, all participants may not be given enough opportunity to express themselves. Consider starting a second group if the number of participants regularly exceeds 12.

5. Establish ground rules for the group. Post these rules prominently at each meeting and remind participants of the rules where necessary. Suggested rules include:

   a. Whatever is said in the group stays in the group.
   b. Use “I” messages, not “you” messages (In other words, do not blame others).
   c. Don’t give advice unless it is requested.
   d. You don’t have to talk if you don’t want to.
   e. Don’t use humor to cover your pain.
   f. Be as honest as possible.
   g. Do not judge other group members.
   h. One person speaks at a time.
   i. Listen to each other.
   j. It is ok to disagree.
   k. Each person’s contribution is valuable.
   l. Criticizing specific medical professionals is not allowed.

6. Many groups encourage the exchange of telephone numbers or an internal phone list to provide support to members between meetings. Ask your members if they would like to participate. Establish ground rules for this phone network as a group, such as restricting calls after 9:00 PM. Your group may also be interested in an email network.

7. Decide whether to offer refreshments. If food and beverages will be available, keep in mind the special health concerns for Myasthenics and try to ensure that a variety of healthy foods is available. Decide whether the group will pay for food and beverages that are provided, or people will take turns bringing the refreshments.

**How do I Facilitate the Conversation Effectively?**

The facilitator’s responsibilities are to:

   a) Use appropriate self-disclosure with members. Give members a sense of your background and knowledge of Myasthenia Gravis.

   b) Arrive early and be prepared to lead the discussion.

   c) Initiate and guide discussion among group members. Facilitators do not give specific advice or direction about decisions that members need to make, but enlist the resources of the group to listen to members’ concerns.
d) Ensure that the group discussion stays on topic and within group guidelines. Allow for flexibility if a member has something critical to discuss (e.g. health crisis).

e) Keep group discussions non-judgmental and informative.

f) Model good listening. Expand on members’ contributions by elaborating or clarifying what was said and asking for feedback from the group.

g) Make certain that each person who wishes to speak is given an opportunity. Encourage active participation of all members of the group.

h) Try to discourage core group members from forming a clique. Promote inclusive behavior among all participants.

i) Regularly communicate to the members that the group was established for their benefit and offer members an opportunity to express their needs so they believe the group is meaningful and productive for them.

j) Evaluate emotions among group members often. The facilitator should be prepared for dealing with a variety of emotional reactions to MG, including frustration, sadness and anger.

k) A few minutes before the end of each meeting, ask the group whether anyone has any final comments that relate to the current discussion. Summarize the discussion that took place during the meeting, and then remind the group of the next meeting date and topic. End the meeting on a positive note.

**Communication Techniques**

A number of communication techniques can be used by facilitators during group discussions. Effective facilitators have developed good listening skills and are able to help a group focus its attention on the chosen topic while observing and acknowledging member behavior. Below are some techniques that can be used in facilitating support group discussions:

1. Active listening
   
   a) Listen to what the member is saying and try to understand what the message means or how the member is feeling.

   b) Restate the member’s message in your own words, identifying feelings the person is expressing (for example, if the member says, “I am tired of taking my medications. The side effects are so awful,” you can respond by saying, “So, you’re saying that you’re frustrated by the side effects of your medications and want to stop taking them?”).

   c) By helping people talk through their issues in the group, they can arrive at a solution, which can build trust within the group and maximize positive emotions within the group.
2. Defer self-focus
   a) Focus on the meaning and intention of others’ thoughts and listen empathetically. Empathy is the identification with and understanding of another's situation, feelings and motives.
   b) Concentrate on understanding the other’s feelings conveyed in their comments.
   c) Resist the temptation to own or outdo another member’s experience. Defer your own contribution until the other person is through discussing his or her own issues. Expect group members to do the same.

3. Discourage verbal attacks or harsh criticism. If someone’s behavior is inappropriate, focus on the behavior, rather than the person, when redirecting. In other words, if someone talks over another person, your response would be, “Jim, please remember the ground rules and allow Jane to finish her thought before you speak,” rather than “Jim, you aren’t being very thoughtful, interrupting Jane like that.”

4. Disruptive behavior can be managed in a variety of ways.
   - Minimize disruption
     - Model appropriate behavior
     - Treat each member with respect and patience
     - Post ground rules prominently at each meeting
     - Establish clear roles and responsibilities for the leader and members
     - Focus on behavior, rather than the person
     - Keep members on topic
   - Leader confrontation
     - If confrontation must be used, decide whether you should approach the person one-on-one or within the group
     - Use “I messages” to minimize blame and leave communication lines open
     - Inform member that if disruption does not stop, negative consequences would result, and follow through on implementing the consequences.
   - Group member confrontation
     - In certain situations, choosing a group member to confront the disruptive member may be more effective than confrontation by the group leader.
     - If a group member confronts the disruptive member, the procedure listed above can be helpful in resolving the conflict.

5. Evaluation
   - A written evaluation of the group can provide some helpful feedback from the members. A sample evaluation is included in Appendix C.

6. Change in leadership
   - If the group leader must discontinue work with the group for any reason, it is helpful for the group to talk about their feelings about the termination.
• The leader should express why he or she is leaving, discuss the group’s positive qualities and express his or her own feelings about leaving the group.

• The leader who is leaving should select a new leader and inform that person of the group’s goals, characteristics of members, current tasks and difficulties. The new leader should be introduced to the group by the leader who is leaving.

These guidelines were developed to help chapters of MGFA initiate, facilitate and maintain support groups. It is important to remember that each group is unique and has its own strengths and challenges. Expect your group to experience "ups and downs" in terms of attendance and enthusiasm. It's natural and should be expected. Volunteer facilitators may find it helpful to consult with people who have facilitated successful support groups if faced with additional questions. If you would like to discuss specific concerns or have questions, please contact the Chapter Relations Manager at the national office at 1.800.541.5454.

Thank you for your willingness to offer a support group for people with Myasthenia Gravis in your community. These groups help the Myasthenia Gravis Foundation of America further its mission 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.
Appendix A

Checklist for Meetings

✓ Name tags
✓ Paper
✓ Pens
✓ Refreshments
✓ Printed information about Myasthenia Gravis, MGFA, your chapter and relevant community resources
✓ Written ground rules
✓ Organize chairs into a circle, ensuring that adequate seating is available
✓ Hang signage to direct people to the correct entrance and room number
✓ Emergency contact information for each member
✓ Post directions to restrooms
Appendix B

Sample Flyers
MEETING
NOTICE

WHERE:

WHEN:

TIME:

Peer Support For People Who Are Affected by Myasthenia Gravis. For more information, contact:
Name
Phone
Email
XXX Chapter of MGFA, INC.

invites you to a new support group for patients and their families whose lives have been affected by Myasthenia Gravis

In association with the XXX State Chapter of the Myasthenia Gravis Foundation of America, Inc.

Wednesday, July 16, 2003 - 6:00 p.m. - 8:00 p.m.
Lakeville Community Center, Conference Room
Bring a friend or family member!
R.S.V.P to 555/111-2222 or for more information.

2nd Wednesday of each Month - 6:00 p.m. - 8:00 p.m.
July 9 • August 13 • September 10 • October 8 • November 12 • December 10

4th Wednesday of each Month - 1:00 p.m. - 3:00 p.m.
July 23 • August 27 • September 24 • October 22 • November 26 • December 17

Lakeville Community Center is located in Lakeville off I-35W and Silver Lake Rd.

DIRECTIONS. Come in the main hospital entrance to the Resource Center classroom.

R.S.V.P to NAME: 555/111-2222.

Hosted by FACILITATOR – Name, some identifying information.
Appendix C

Sign-In Sheet
The Myasthenia Gravis Foundation of America does not recommend or endorse any physician, medication or course of treatment. Patients should discuss concerns related to specific medical care with their medical professionals.

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Appendix D

Confidentiality Statement Forms
PLEDGE OF CONFIDENTIALITY

I, ___________________________, am volunteering my time to help carry out the work of the Myasthenia Gravis Foundation of America, Inc (MGFA). I understand that in the course of my volunteer work and experience I may learn certain facts about individuals that are of a highly personal and confidential nature. Examples of such information are medical condition and treatment, finances, living arrangements, employment, sexual orientation and relations with family members. I understand that all such information must be treated as completely confidential. I agree not to disclose any information of a personal and confidential nature to any person not authorized by the MGFA to have such information without the specific written consent of the individual to whom such information pertains.

I also understand that in the course of my work, I may learn certain facts about MGFA considered to be proprietary information. I understand that all such information must be treated as completely confidential and is not to be revealed to any unauthorized source.

I understand that failure to comply may result in my immediate dismissal as a MGFA volunteer.

Volunteer:

______________________________
Signature

______________________________
Print Name

______________________________
Date
CONFIDENTIALITY STATEMENT

As a participant in the _____________________ (support group), I understand and agree that I must hold all personal and medical information regarding other support group members in strict confidence.

The basic premise of confidentiality is that information shared in group meetings will not be discussed outside of that particular venue.

I realize that failure to comply with this policy may result in disciplinary action up to and including my loss of membership in the _____________________ (support group).

I, the undersigned, agree to the principles set forth in the above statement of confidentiality.

________________________________________  __________________________
(Signature)  (Date)
Appendix E

Evaluation Form
Support Group Evaluation

Date:
Facilitator:

1. The group facilitator was prepared for meetings. Agree_____________________Disagree
   Comments:

   1 2 3 4 5

2. The topics of discussion were relevant to my needs. Agree_____________________Disagree
   Comments:

   1 2 3 4 5

3. The meeting time and location are convenient for me. Agree_____________________Disagree
   Comments:

   1 2 3 4 5

4. Overall, the group met my expectations. Agree_____________________Disagree
   Comments:

   1 2 3 4 5

5. I would recommend this group to others. Yes/ No
   Comments:

6. Future topics I’d like to see discussed:

7. My suggestions to improve the group are:

   Please return evaluations to:
Appendix F

Press Release
Sample Press Release [Use your chapter’s letterhead]

For Immediate Release
Date: March 20, 2003

Contact: Jane Doe, Support group leader, 555.555.5555.

NEW SUPPORT GROUP ESTABLISHED FOR PEOPLE DIAGNOSED WITH MYASTHENIA GRAVIS AND RELATED DISORDERS.

A new support group for people who have been diagnosed with Myasthenia Gravis, an autoimmune neuromuscular disorder, has been initiated by the [Your chapter name] Chapter of the Myasthenia Gravis Foundation of America, Inc.

People affected by Myasthenia Gravis, including family and friends of Myasthenics, are invited to attend this group. There is no charge to participate and registration is not required. The first meeting will be held at the Central Community Center, Lakeside Room, on Wednesday, March 26, 2003 from 7:00-8:30 PM.

The group will regularly feature speakers on the topic of Myasthenia Gravis and related issues.

The Myasthenia Gravis Foundation of America was founded in 1952 and operates chapters throughout the country. Its 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.

For additional information, please contact Jane Doe at 555.555.5555 or email: MG@MGchapter.org.
Appendix G

QUOTES

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

Who then can so softly bind up the wound of another as he who has felt the same wound himself? – Thomas Jefferson

Listening is such as simple act. It requires us to be present, and that takes practice, but we don’t have to do anything else. We don’t have to advise, or coach, or sound wise. We just have to be willing to sit there and listen. If we can do that, we create moments in which real healing is available. Whatever life we have experienced, if we can tell our story to someone who listens, we find it easier to deal with our circumstances. – Margaret J. Wheatley

To listen is to receive. – Elie Wiesel

The world is your mirror and your mind is a magnet. What you perceive in this world is largely a reflection of your own attitudes and beliefs. Life will give you what you attract with your thoughts. Think, act and talk negatively and your world will be negative. Think and act and talk with enthusiasm and you will attract positive results. – Michael LeBeuf

Whatever comes, this too shall pass away. – Ella Wheeler Wilcox

It is a curious thing in human experience but to live through a period of stress and sorrow with another person creates a bond which nothing seems able to break. – Eleanor Roosevelt

Don’t walk behind me; I may not lead. Don’t walk in front of me; I may not follow. Just walk beside me and be my friend. – Albert Camus

Not life, but good life, is to be chiefly valued. – Socrates

Go confidently in the direction of your dreams. Live the life you have imagined. – Henry David Thoreau

Listening is noting what, when and how something is being said. Listening is distinguishing what is not being said from what is silence. Listening is not acting like you’re in a hurry, even if you are. Listening is eye contact, a hand placed gently upon an arm. Sometimes, listening is taking careful notes in the person’s own words. Listening involves suspension of judgment. It is neither analyzing nor racking your brain for labels, diagnoses, or remedies before the person is done relating her symptoms. Listening, like labor assisting, creates a safe space where whatever needs to happen or be said can come. – Allison Para Bastien

The most basic of all human needs is the need to understand and be understood. The best way to understand people is to listen to them. – Ralph Nichols
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Parent to Parent of PA. Starting/Running Support Groups.


