

### IMPORTANT PHONE NUMBERS

Phone #

Address

This image shows a single sheet of bright yellow paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There is no handwriting or printed text on the paper.

Part of the LDF's Lyme Disease Self-Help Program

**ORGANIZING & CONDUCTING  
A LYME DISEASE  
SELF-HELP GROUP**

# INSTRUCTION MANUAL



## Lyme Disease Foundation ("LDF")

384-G Merrow RD, Tolland CT. 06084  
1-860-454-8909 [www.lyme.org](http://www.lyme.org)

[www.lyme.org](http://www.lyme.org)



# LYME DISEASE FOUNDATION

One Financial Plaza, Hartford, CT 06103

Dear Potential Group Leaders:

There are a few things that we at the Lyme Disease Foundation would like to say to the leaders of Lyme Disease Self-Help Groups.

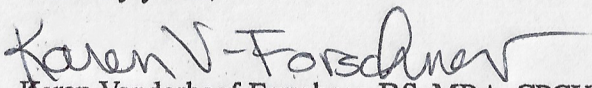
First, thank-you. The Lyme Disease Foundation (LDF) appreciates the energy and conviction that you have in starting this difficult but rewarding task. As you may know there are a great many steps that must be taken to form a group that will run effectively and efficiently. Until you have found others who are willing to put in the same amount of dedication and energy that you are, starting and maintaining a group may be very time consuming and emotionally draining.

Please remember that you are one person and that you have limits - to your time, compassion, emotional well being and to your family's patience. Leaders must have a core group or at least one other person in the group with whom to share responsibilities.

Anger, frustration, helplessness, and isolation are frequent issues that people adversely impacted by LD need to work out. If you have not worked through these issues, you may not be able to give the appropriate responses necessary to help the members of your group.

We hope you find the leadership experience rewarding. If you do establish a self-help group please let us know because we would like to add you to our list.

Sincerely yours,



Karen Vanderhoof-Forschner, BS, MBA, CPCU, CLU  
Chair, Board of Directors

## I. GUIDING PRINCIPLES FOR LYME DISEASE SELF-HELP GROUPS

---

- **A Lyme disease (LD) self-help (S-H) group's mission is to assist people** who are adversely affected by Lyme disease and other tick-spread disorders help themselves to recovery. LDS-H Groups carry the message of recovery to those who still suffer.
- **Group members are those people negatively affected** by Lyme disease (or related disorders) with a desire to help themselves or loved ones recover from suffering.
- **A group's mission is accomplished** when members experience psychological recovery and can cope with life's "ups" and "downs".
- **Groups are informal and led by volunteers.** Groups are led by ordinary people with extraordinary commitment. They do not substitute for professional help.
- **Groups use the shared leadership concept.** This means that members share the responsibility for guiding the group.
- **Groups are self-supporting.** Experience has shown that nothing can destroy a group's bond as quickly as disputes over money. However, member donations to cover the costs of copying, coffee, etc. are encouraged as a shared responsibility.
- **Groups recognize member privacy & confidentiality.** Members attending meetings are assured confidentiality by other members.
- **Group members are responsible for their own decisions.**
- **Group members who are "recovered" will consider donating their time to help the Lyme disease cause.** This includes starting a Self-Help Group, being a mentor to someone who needs extra support, facilitating a meeting, or volunteering to conduct community education.







the talker into your discussion by asking for an opinion. Assertive confrontation may be appropriate, especially if the person seems immune to gentler suggestions. Ignore short, occasional side conversations. These discussions are fairly harmless.

- **Poor speech pattern or choice of words.** The idea may be good but the manner in which it is said could be all wrong. Help this member. Repeat the main ideas in your own words. "In other words, you are saying ....." It is becoming increasingly difficult to have conversations that are 100% "politically" correct. Remember, some people with Lyme disease suffer from cognitive difficulties and this may cause them to have great difficulty in translating thought to words. Be forgiving and protect the speaker from ridicule.
- **Definitely wrong.** If he is contrary to group thought, say, "Well, that is one way of looking at it," and then go on.
- **Personalities.** Where there is a dispute interrupt the conversation with a direct question on the subject. Bring another member into the discussion. Ask that personalities be left out.
- **Bored.** Find the member's interest. Call on the member for input.
- **Silent member.** A silent member is not necessarily a deficit. New members may not feel comfortable expressing feelings or ideas in front of people whom they have just met. New members may need a few meetings before they feel free to talk. However, when this breaking-in phase seems to be prolonged, the leader or other member can invite participation, for example: "I know that other members have had experiences similar to the one that Barb just described. Would any of you like to share your reactions with the group?"
- **Shy, hesitant.** Ask direct questions which you are sure he can answer. Ask the member for agreement or disagreement. Build him up in the eyes of the group.
- **Authoritarian advice giver.** For the know-it-all, one strategy is to use this person's assertions for a springboard, "Derrick, many of us used to think that way, but our experience with ... helped us to change our thinking a little."
- **Domineering facilitator.** When a facilitator begins to dominate a group in a negative way it is time for members to talk with the co-leaders. In some situations, the only way to handle a domineering person may be by honest private discussion. It is important to be tactful and to keep the good of the individual as well as the group in mind. The facilitator can avoid the situation by monitoring the percent of time he or she is talking and providing solutions. If a facilitator is doing the majority of talking - then be quiet and let the group work toward the solution on its own.
- **A Member is Stuck.** A member is "stuck" when that person has the same problem(s) month after month and is making no progress forward. This person is unwilling to try something different or to view the situation from another angle. The tip-off to this person is

"Yes, but..". This person will acknowledge any suggestion made by saying "yes" and then saying "but," which puts road blocks in front of all suggestions given. This person is just not ready to make a change. You can say, "I hear a lot of yes, but's'. You need to decide if the situation is serious enough to make a change". Then move the discussion on to another members problems.

- **Last Minute Bomb.** This is a common problem for members of Self-Help Groups. The member who drops "the bomb" remains quiet throughout the meeting and in the last few minutes speaks up about a major personal trauma, e.g. my husband has just left me, I was fired today, my child is seriously ill. This is a pattern with some people. It is unclear why they wait, but the meeting still must end on time! This person had time to discuss the issue but waited. The facilitator should suggest the person take some phone numbers from the *Lyme Disease Phone Support List*. This way the person will have someone with whom to talk until the next meeting.

## II. ANGER

When trying to understand people's anger in S-H Groups, it might be useful to think of two different types of anger: Situational Anger and Underlying Anger.

**Situational Anger** is in response to something that happens to someone, such as a loss, a broken promise, or a perceived threat. As such, there is an identifiable cause and a focus, or object that the person is angry at.

**Underlying Anger**, on the other hand, can be thought of as a long-term and generalized state of hostility toward the world or a major part of it (toward men, for example, or toward women). It usually stems from a lifelong set of experiences that, individually, might have produced Situational Anger, but over time have built into a deep and stubborn rage that unfairly targets people or situations that have little to do with it. Underlying anger strongly resists efforts to diffuse it by laypeople and professionals alike.

### A. Situational Anger

By far the more common type, Situational Anger is easier to deal with, and in most Self-Help Groups should be an expected and workable part of the recovery process. Although it is usually directed *at* people, it is almost always *about* events or situations.

#### 1. Anger about Something Outside the Group

Someone may be angry at a spouse, for example, but the anger is probably directly related to something the spouse said or did, or about an ongoing situation in which the spouse is involved. Consider the example of a wife who discovers that her husband has been having an extramarital affair. She is angry at him because of what he has been doing and because of the situation that his actions have now created.



## H. Meeting Topics

S-H Group members often find healing and inspiration in the advice of others. Inspiration is built into some of the most successful Self-Help groups. Most of the 12-step anonymous groups start with a member who tells a personal story about overcoming some obstacle or finding a positive change in the direction of one's life. This 10 minute story is followed by the group input and discussion.

Topics to consider for the meeting include:

- Sharing family responsibilities to ease the burden on the LD patient.
- A family member/ friend has LD and I feel lost in the shuffle.
- Time management. Cutting back on life's obligations.
- Finding the good points of life.
- I'm mad about everything. How can I help myself?
- Reducing guilt.
- Stages of grief, the natural way we cope with adversity.
- Becoming more positive about life.

## I. Publicity

The best way to find potential members is to use publicity. Post flyers about your group in libraries, post offices, supermarkets, community centers, shops, churches, and hospitals. Also, send announcements about the group's mission, meeting place & time to local newspapers, radio and TV stations. Feature articles (with interviews done outside of the meeting time) attract members. And, write a "letter-to-the-editor" to local newspapers explaining your group's existence and purpose.

## III. GROUP BEHAVIOR

Each group will have its own "ambience". This atmosphere is a function of leadership and membership development. Established groups will function differently than new groups. What is appealing to one group member may be unappealing to another member. This is why members may shift from one group to another.

Strengthening a group's cohesiveness and fullness is important for functioning at the highest level possible. Key factors to accomplishing this are: developing a sense of group unity and member sharing; improving the understanding of each person's problems; improving member communication ability; and helping people help restore themselves to improved health.

### A. Active Listening

The key ingredient in most helping relationships is the sense on the part of the person being helped that he or she is being listened to. The term "active listening" refers to everything that someone might do in order to not only listen to a person, but also to let that person know that

he or she is being listened to.

We all use certain cues to let people know we are listening to them. Examples are: nodding our heads in agreement, saying "Mm hnm", opening our eyes in shared disbelief at something, etc. The following clarification techniques carry the process even further, indicating that you are not only listening, but also thinking actively about what is being said, regardless of whether you agree or disagree.

- **Restate** - Repeat what a person said using slightly different wording. Emphasize one part of the message over another, using specific word choices, vocal tone or emphasis.
- **Question** - Request additional information in order to clarify a statement. This ensures not only that you understand what you're being told, but also uncovers unconsidered issues.
- **Focus** - Clarify exactly what the conversation is about by labeling the larger context in which it occurs. This helps regain perspective about how the ideas fit together.
- **Reflect feelings** - Identify what you perceive as the feeling underlying what a person is talking about or *around*. This can alter the intensity level of the conversation because you may be able to find the *true* problem.
- **Validate** - Legitimize a person's statement by indicating that it makes sense to you, given what you see as the underlying feelings the person seems to have.
- **Confront** - State the inconsistencies between what a person says and does. This forces a person to confront his own confusion.

### B. Advice/Suggestions: Good & Bad

Some S-H Groups thrive because they know when and how to give advice. But members who repeatedly give inappropriate advice can be heading for trouble. The kind of advice that's rich in experience, information, and caring, and delivered at a time when it's really wanted, rarely gets rejected.

Things to consider before offering advice:

- **Is there a strong need for your advice?** How willing is the other person to receive suggestions? When someone is disclosing a problem, it's common for others to think that the speaker is looking for advice. Sometimes though, this person just wants to unburden and be listened to. The more complicated a person's problem, the more likely it is that if a simple suggestion for some change is really the answer, it would have already been done.
- **Does the person want advice or just want to talk?** Ask the member!
- **Are you informed?** Accept that you will never know *all* of the facts involving the other person. However, explore, using questions, the person's position and try to see the issue from several sides. And,



make suggestions from the various viewpoints.

Many times the problem presented is not the "real" problem. Keep probing for some deeper concern or issue. As the person talks, the real problem often arises.

It's easy in a S-H Group when everyone shares a common concern to assume that one person's experience is the same as yours. It often is, and that's one of the greatest strengths of S-H Groups. But when it's not, and you don't fully understand the problem, advice can be half-baked. So take the time to get additional information before trying to help.

- **Have you had success with a comparable problem?** Are you seen as knowledgeable, competent, or experienced in the matter? If the person needing advice knows that you have learned about dealing with a specific problem by living through it, or picking up practical wisdom from others, then usually your advice will be well received. It is not unusual for a suggestion from a family member to be ignored, then accepted when given by strangers.
- **Do you have empathy?** Exchanging personal advice in a group is a lot easier when people feel deeply understood.
- **Does the member understand that he or she is responsible for making the decision?** Some people will act upon any suggestions - whether good or bad. If the person with the problem is unable to make his or her own decisions you should avoid making any specific suggestions for solutions, but rather present a variety of nonspecific options.

#### IV. MEMBERSHIP

LD S-H Group members are those people being negatively affected by Lyme Disease and desire to help themselves or loved ones recover from suffering.

In a S-H group, *facilitating* a group discussion is not the sole responsibility of one person but it *is the responsibility of the entire group*. A shared sense of responsibility enhances a group's ability to help members help themselves.

##### A. Member Guidelines

There are specific guidelines for members to follow in order to maximize the group experience.

1. We are a group of people affected by Lyme disease or other tick-spread disorders, with a common bond of sharing our troubles, understanding, strength, wisdom and working toward recovery.
2. I know what we share is confidential and that my comments will not be repeated outside of the group. I will not repeat specific comments made by any group member.
3. I have the right to remain anonymous.
4. I listen, explore options, and express my feelings. I do not judge.

5. I have the opportunity to participate in discussion and the right to remain silent.
6. I will actively listen and avoid side conversations.
7. I share the responsibility for making the group work.
8. I recognize the need to help others, since I have benefited from the group, by offering advice to others, serving as a co-leader, starting another group, or volunteering to conduct community education. However, I am not obligated to do anything.
9. I know the decisions I make are my responsibility.
10. I have the right to say things I feel, even though I may not know how to clearly state my feelings. Although it is O.K. to say things and explore the way I feel, it is not O.K. to hurt people.
11. I will try to help members feel comfortable.
12. I will encourage positive comments and new viewpoints lest the conversation deteriorate into a "gripe" session.
13. I will try to recognize when a member's problems are beyond the group's ability to help and will suggest the person seek professional assistance.
14. I will allow members to vent their feelings without taking their feelings personally; often this must be done before positive feedback can be given or received.
15. I will not wait until the last minutes of the meeting to bring-up a life trauma that has just happened. I understand that even if I have a major trauma, the meeting will close on time.
16. I know that if I need help outside of the meeting time, I can call someone from the *LD Phone Support/Buddy List*. I will keep the numbers on this list strictly confidential and will not share them with anyone else.
17. I will thank the leaders for providing the opportunity to attend the meeting.

##### B. Member Needs

It is important to remember that members have needs for which they seek fulfillment from a group.

- To belong
- To contribute
- To be accepted by others
- To develop status
- To be heard
- To have dependence
- To have freedom
- To foster loyalties
- To have power



## **V. GROUP LEADERSHIP**

The leadership of each Self-Help Group should be composed of at least two key people:

The **Facilitator** is responsible for choosing the topic for the meeting and guiding the discussion. This person should also keep in touch with other groups and the LDF. This person should train co-facilitators. At least 4 times a year, a co-facilitator should facilitate the meeting.

The **Coordinator** handles the logistics of the meeting (time, place, copies, table, chairs), coordinates publicity and maintains contact with other groups and the LDF. The coordinator should train co-coordinators.

The facilitator, coordinator, co-leaders and other members have the right to exclude certain people from attending meetings. People who should be excluded are those who: come just to observe, solicit business, severely disrupt the meeting or have problems that are so serious that they need professional help before the person can continue with the group.

One element of leadership is to mentor new leaders - co-facilitators and co-coordinators. While most people agree that shared leadership is an important goal to strive for in S-H groups, there is little in the way of written guidelines and suggestions on how to achieve this elusive ideal. With an initial reminder that every group (and every person) is different, and that with every advantage there is some disadvantage or trade-off in group process, the following ideas might be considered among those who can distribute the sense of ownership and responsibility for leadership throughout the whole group, easing the burden on any one individual and ensuring both openness and continuity for the group.

### **A. Think "Shared Leadership" from the Beginning**

Set the precedent of sharing tasks and resources while the group is forming, so that there are at least two people taking responsibility for the group, and no one person does it all. In the short run it may seem easier to do things completely by yourself, but such a pattern is very easily set and quite hard to break; you then become the expert, and the "best person to do it" at the cost of member joint ownership.

It is important to deliberately cultivate a sense of shared responsibility. Members should feel committed to the group and be encouraged to contribute whatever skills or talents they have. Although member involvement is important, members should not be made to participate due to guilt.

### **B. Rotate Leadership and Other Tasks**

Opening the doors of leadership to members never guarantees an efficient organization. It may prove more chaotic since it is often easier to get things done by doing it ourselves. Unfortunately, this robs members of the benefits gained by assuming an active role. Discover the talents of

group members and give them opportunities to exercise them. A major strength of a S-H group should be that no one person has all the skills or shoulders all of the responsibility. It is also true that some people will not work out in leadership roles. If this is the case, discuss the situation with the person and let her try again at a later date. Often when things are not going well a leader knows it and welcomes a way to back-out gracefully.

A co-leader can help the leader during the training period. This strategy is applicable to many tasks and functions, fosters participation among the group, and promotes a sense of continuity over time. A few times each year, have the co-facilitator run the meeting and the co-coordinator arrange the meeting.

Based on comments made in the meetings, quietly and perhaps outside of the group, ask individual people to help you with specific tasks and projects. This gives them experience without too much responsibility and links people together.

Also, remember to make room for others. Be sensitive to people's signals and know when to let others do the work. However, be available for advice and support.

## **VI. FACILITATING GROUP DISCUSSION**

Remember that you are not responsible for the actions of your group members. You are not the problem solver. The best that you can do is give each member the chance to speak freely and encourage members to listen. If members aren't willing to work on their problems, you cannot make them do so.

### **A. What a S-H Group needs from a facilitator**

1. **Set Limits**, including time limits, topics for discussion, and program topics. Stick to the agenda and yet be flexible. When the discussion gets off track pull it back by saying so. If there is good energy or an issue of overriding importance, you may let the discussion flow, until it gets too far afield or seems to be avoiding the topic at hand. Another limit is to end the meeting on time.

Limits should also be placed on group leader dependency. The facilitator must set limits on member access to the facilitators personal time. Members are not allowed to call facilitators at all hours for support. The ideal is for the facilitator to be available only during group time. Phone support volunteers are responsible for emotional support outside group hours. This is where the *LD Phone Support List* comes in handy!

2. **Maintain an informal and friendly atmosphere** in which cooperation, production and participation can be achieved.
3. **Initiate discussion and stimulate participation.**
4. **Remove blocks to good discussion.**
5. **Maintain a well-defined discussion area** and allow questions that are pertinent to the topic.



6. **Provide opportunities for the expressing of all points of view,** encourage members to participate & prevent monopoly of discussion.
7. **Understand opinions given** by the group members.
8. **Help members progress toward recovery.**

#### B. Techniques to facilitate for success

Encourage individual participation and group cohesion. Conflict and disagreement are present, normally, within every group. It is the responsibility of the leader to support the strengths of individual members and an atmosphere in which members support each other. People will assume different roles within groups. Leaders need to allow members as many constructive roles as possible.

1. **Maintain eye contact with all participants.** By simply looking at someone and smiling, you help that person be a participant, even if the member hasn't said anything for a while.
2. **Address people by their first name.** This helps everyone learn one another's name and makes participants feel that you care what happens to them.
3. **Be aware of group energy and individual relationships.** Glance around the room frequently to check expressions and body language. You may call on people who are fidgeting and appear to be bored.
4. **Let one person talk at a time.** If someone does not get to finish a point, go back to that person. If someone tries to contribute, but can't get into the conversation, give that person the floor.
5. **Keep discussions on a personal and feeling level.** Challenge generalizations, such as "all men/women are..." by asking those present if the statement just made pertains to them. Encourage "I" statements along the way. You may feel that you need to share some of your own personal experiences to pave the way.
6. **Listen** so that you can give feedback, extend support, and call attention to similar or conflicting points of view.
7. **Let members speak first** and throw questions directed at you back to the group. For example, "What do all of you think?"
8. **Discourage scape-goating and monopolizing.**
9. **Encourage a sense of humor** but de-emphasize clowning.
10. **Understand blocks to communication** and how to help members more effectively relate their ideas.
11. **Have members be accountable** to one another, not just to the leader.
12. **No person should diagnose, recommend treatment, or doctor shop.** It is important that the group be nonthreatening to health care professionals who want to refer potential members to the group. Remember, there are many facts about a person's medical history that the member will keep confidential; you will not have all the facts.

#### C. Functions Self-Help Group Facilitators strive to provide:

1. **Information/opinion giver and seeker.** Offers and asks for facts, opinions, ideas, suggestions, and relevant information to discussions.
2. **Diagnoser.** Determines sources of difficulties the group has in working effectively and in accomplishing its mission.
3. **Reality tester.** Examines the practicality and workability of ideas, evaluates alternative solutions, and applies them to real situations to see how they will work. Shows relationships of ideas by comparing various suggestions. Helps the group separate fact from opinion. Asking questions becomes especially important when members of the group are expressing their gripes and prejudices.  
To stress something someone has said as opinion rather than fact, use questions such as these:  
a) "Do you know that as a fact, or is it your opinion?"  
b) "Can you give us the source of your information?"
4. **Encourager of participation.** Getting 100% participation is not an easy job and with some groups it is impossible. One way to break the ice with quiet members is to pick out a question of opinion which can be answered by yes or no and go around the room asking each member's opinion. Warmly encourages everyone to participate, giving recognition for contribution, demonstrating acceptance and openness to ideas of others; is friendly and responsive to group members.
5. **Compromiser.** Persuades members to analyze their differences, searches for common elements in conflict, and tries to reconcile disagreements.
6. **Tension reliever.** Eases tensions and increases the enjoyment of the group members by joking, suggesting breaks, and proposing enjoyable approaches to group work.
7. **Communications helper.** Shows good communication skills and makes sure that each group member understands what other members are saying. If someone has trouble making a point or states an idea vaguely, help clarify the point. If people do not understand, have someone restate the issue. If there is a conflict between two members, spell out the points of disagreement so the whole group can help settle the difference.
8. **Active listener.** Listens and serves as an interested audience for other members and is receptive to others' ideas.
9. **Trust builder.** Accepts and supports openness of other group members, reinforcing risk taking and encouraging individuality.
10. **Guides the discussion, but does not give "answers".** Facilitators must not act as though they know the truth and are there to pour it into empty heads. The facilitator should guide the discussion along orderly and fruitful lines. The group should pool its knowledge and its thinking rather than receive answers from an authority. Never say, "I'll explain this to you." Do say "Let's see if we can get to the core of this problem and find several options for solutions."



11. **Don't be too insistent in giving your own opinion.** The group will resent the leader who gives opinions too frequently. However, don't try to make the group feel that you have no opinions. For example, after a thorough discussion of a problem, the facilitator might say, "Here's my opinion on this. You're entitled to yours, of course. But I think you should know how I feel too."

#### D. Checks to Analyze the Success of the Group

1. **Attendance.** If the number does not drop significantly *during* your program, this indicates interest and success.
2. **Participation.** If almost everyone speaks, you are doing an important part of your job well. Don't worry if a few do not participate.
3. **Keeping on the track.** Did the group keep to the general subject you planned or did it wander off and get confused?
4. **Group feeling and respect.** Did members of the group accept and respect the ideas of other members of the group? Was there a real spirit of give and take?
5. **Attitudes toward the leaders.** Did the group members share responsibility for the group? Did they feel that you were the boss? Did everything you say go? Or, did they feel that you were just one part of the group?
6. **Members' attitude at the conclusion of the meeting.** If members are leaving the meeting more depressed than when they came, something is going wrong. You need to reevaluate the discussion.
7. **You are getting results when:**
  - Individuals feel they belong to the group.
  - Members improve their ability to function and feel better about life.
  - Members have developed a better way of analyzing and solving problems.
  - Referrals to the group increase, including referrals from members who have returned to full functioning.
  - Members become "done" (recovered) and move on with their lives.
  - Members move to leadership positions, become community educators, or start their own S-H Groups.

### VI. YOUR FIRST MEETING

The goal of the first meeting is to break down the barriers of strangeness that separate people. People tend to withdraw when they are uncertain of the other group members' reactions. Getting to know each other and being able to predict each others' reactions will help.

For the first meeting have a core group greet members as they arrive. A person's initial feeling about the group is important. It is important to get the group started on time. Meeting activities may include speakers and films, followed by a discussion in which all can participate. Personal contact reinforces people's attendance as well as taking a part in specific tasks.

#### A. Helpful Hints to Make your First Meeting a Success

1. Before your first meeting, be sure the core group has a clear idea of the mission, membership and facilitation methods.
2. Arrange the room so that all chairs face the facilitator (preferably a circle), and be sure the light levels and temperature are comfortable.
3. Start and finish your meeting on time.
4. Encourage feedback from each member. And, when given feedback avoid being defensive and seriously consider the ideas.
5. Have *Lyme Disease Phone Support List* available. Many groups encourage the exchange of phone numbers to provide additional support to needy members. This can be done by using a sign up sheet, in which members who wish to receive phone calls write down their number and first name. Anyone needing help can take these numbers and call whenever necessary.

#### B. Meeting Structure

1. **Greet members** as they come in.
2. **Formal opening** - Open with a statement covering key concepts: the mission statement, disclosure of volunteerism and shared leadership.
3. **Business** - e.g. who will cleanup, where literature and donation jar are, rental of meeting space, input for future discussion.
4. **Introduction of leaders & members** - Be sure new members are given an opportunity to introduce themselves and briefly tell their "personal story". Some groups prefer to have new members talk after other members. This gives the new members an understanding of how to summarize their own problems. Members have the right to use just their first names or stay anonymous. And, some members may just say "Pass" and say nothing. Do not pressure anyone. It may take several meetings before some people feel comfortable enough to participate and share openly. This is the time to ask new members about their expectations of the group.
5. **Topic of the day** (speaker, discussion, etc.)
  - Tell the group members what the topic of the day is.
  - Have the "story" told by the facilitator or co-facilitator.
  - Move to the discussion of the topic and then group problems. If someone gets off the track, interrupt that person as tactfully as you can, "That's a good point, but I'm afraid we're getting away from the main subject. The problem we're discussing is ....."
6. **Formal close.** Before adjourning announce the time and place for your next meeting. Have a formal closing. It is important that some signal be given to indicate that the meeting is formally closed. Members should be reminded of the time and place of the next meeting. You can end with an uplifting note or phrase like - *I hope you find your problems seem lighter and your days are brighter.*



### C. What to Avoid During the Meeting

Avoid discussions that do not help people cope with their problems. Time spent on other issues decreases the time spent on Self-Help issues.

- **Doctor bashing.** Discussing a health care provider by name is both nonproductive and can cause physicians to fear referring patients to a group.
- **Recommending medications** is practicing medicine without a license and could involve you in legal problems with patients.
- **Political discussions.** While noble in intent, it is easy to move into the "black hole" of endless non-solutions. Worse yet, these discussions could seriously depress attendees.

### VIII. KEEPING A GROUP GOING

Maintaining a LD S-H Group requires as much effort as starting one. More, some would say. S-H Groups face the prospect of constantly recreating themselves. Given this, group leaders and members will be well served by remembering the following advice.

The concept of sharing is central to a S-H Group. Sharing helps produce a cohesive group. It sets the tone and establishes an atmosphere of openness and togetherness.

Take time to acknowledge and praise members for their contributions to the group. Remember, if you want people to be actively involved, reinforce participation when it occurs. On the other side, when mistakes are made or opportunities missed, avoid victim blaming. It's of little value to dwell on what might have been or should have been. Rather, chalk it up to experience.

It's not uncommon for groups, after a period of time, to dispense with or downplay the importance of sharing periods. Sometimes groups begin to rely on outside issues alone rather than on mutual exchanges between members. Some have learned the hard way that they have abandoned the very reason their group was started; to share their problems and concerns.

Be realistic. The group will not always be "successful" in its activities or with the people that come into it. Don't traumatize yourself or others with unnecessary accusations and charges. Although S-H Groups are effective for many, they are not a cure-all. Avoid idealizing the group. Be realistic about members who eventually leave the group. It doesn't mean that you have failed. Characteristically, people move into groups, get their needs met and their questions answered, then they move on. Most of these are graduates, not dropouts.

Remember what S-H Groups do best. *Self-Help* is your area of expertise.

Research shows that one of the most consistent drawing factors of Self-Help Groups is the emotional support and sense of community they provide. Whatever else the group does, it must never become a substitute for mutual support. Don't let your sharing time become sidetracked to other activities.

### Conclusion

As our world becomes more impersonal and our lives more complex, people facing problems and life-disrupting situations will be searching for kind words, a sympathetic ear, an understanding nod; and that is something *Lyme Disease Self-Help Groups* do very well!

### IX. BIBLIOGRAPHY

- Adams, Caren, and Jennifer Fay, *No More Secrets*. California: Impact Publishers, 1981.
- Arthritis Health Professional Section, *Self-Help Manual for Patients with Arthritis*. Georgia: Arthritis Foundation, 1980.
- Beattie, Melody, *Co-dependent No More; How to Stop Controlling Others and Start Caring for Yourself*. New York: HarperCollins Publishers, 1987.
- Benjamin, Harold H., Ph.D. & Trubo, Richard, *From Victim to Victor For Cancer Patients and Their Families*. New York: Dell Publishing, 1987.
- Bloomfield, Harold H., M.D. & Felder, Leonard, Ph.D., *Making Peace With Yourself; Turning Your Weaknesses into Strengths*. New York: Bloomfield Productions, Inc., 1985.
- Bosmans, Phil, *Give Happiness a Chance*. Great Britain: Exley Publications, 1989.
- Canadian Mental Health Association, *Coping with Bereavement*. Virginia: National Mental Health Association, no date.
- Canadian Mental Health Association, *Coping: Getting Help When You Need It*. Virginia: National Mental Health Association, no date.
- Decker, John L., M.D., *Understanding and Managing Arthritis*. New York: Avon Books, 1987.
- Donoghue, Paul J., Ph.D. & Siegel, Mary E., Ph.D., *Sick and Tired of Feeling Sick and Tired; Living with Invisible Chronic Illness*. New York: W. W. Norton & Company, Inc., 1992.
- Fishman, Steve, *The Powerful Patient*. New York: Health, March/April, 1993.
- Freudenberger, Herbert J., Ph.D., *Burn Out; How to Beat the High Cost of Success*. New York: Bantam Books, 1981.
- Friedlich, John, *Training Manual for CFIDS Support Group*. MA: CFIDS Association, 1992.
- Gorski, Terence T., *Understanding the Twelve Steps; An Interpretation and Guide for Recovering People*. New York: Simon & Schuster, 1989.
- Grateful Members, *The Twelve Steps for Everyone*. Minnesota: CompCare Publishers, 1990.
- Kanat, Jolie, *Bittersweet Baby: From Heartbreak to Hope*. Minnesota: CompCare Publishers, 1987.
- Kogan, Marcela, *Help Yourself - but not too much*. New York: American Health, March, 1992.



- Kubler-Ross, Elizabeth, MD, *On Death and Dying*. New York: MacMillan Publishing Company, 1970.
- Kushner, Harold S., *When Bad Things Happen to Good People*. New York: Avon Books, 1980.
- LeMaistre, JoAnn, PhD, *The Emotional Impact of Chronic Physical Illness*. California: Bay Area Lupus Foundation, Inc., 1981.
- Lerner, Harriet Goldhor, PhD, *The Dance of Anger*. New York: Harper & Row, 1985.
- Mackenzie, Alec, *The Time Trap*. New York: McGraw-Hill, 1972.
- No Author, *Alcoholics Anonymous; The Story of How Many Thousands of Men and Women Have Recovered from Alcoholism*. New York: Alcoholics Anonymous World Services, Inc., 1976.
- No Author, *The Surgeon General Workshop on Self-Help and Public Health*. U.S. Department of Health and Human Services: Held at the University of California, Los Angeles, September 20-22, 1987, U.S. Government Printing Office, 1988.
- No author, *The Twelve Steps and Traditions*. New York: Al-Anon Family Group Headquarters, 1986.
- No author, *Alcoholism a Merry-Go-Round of DENIAL*. New York: Al-Anon Family Group Headquarters, 1969.
- No author, *Can Support Improve Survival?*. Consumer Reports, February, 1993.
- Schiff, Harriet Sarnoff, *Living Through Mourning; Finding Comfort and Hope When a Loved One Has Died*. New York: Penguin Books, 1987.
- Stearns, Ann Kaiser, *Living Through Personal Crisis*. New York: Ballantine Books, 1984.
- Sternbach, Dr. Richard A., *Mastering Pain; A Twelve-Step Program for Coping with Chronic Pain*. New York: Ballantine Books, 1987.
- Tatelbaum, Judy, *The Courage to Grieve*. New York: Harper & Row, 1980.
- Wegscheider-Cruse, Sharon & Cruse, Joseph, M.D., *Understanding Co-Dependency*. Florida: Health Communications, Inc., 1990.