

ORGANIZING & CONDUCTING A LYME DISEASE SELF-HELP GROUP

FACILITATOR PANIC BUTTON MANUAL

... when things start to go wrong.



LDF LYME DISEASE FOUNDATION

IMPORTANT PHONE NUMBERS

Name _____

Phone #

Address

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

FACILITATORS PANIC BUTTON MANUAL

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I. STRATEGIES TO CORRECT NONPRODUCTIVE BEHAVIOR

It is helpful to have group guidelines to which all members can refer when there is a problem. These guidelines usually specify behaviors which are acceptable and those which are unacceptable.

The facilitator is expected to take the lead when "problem" behaviors disrupt a group. If you feel uncomfortable with something that is being said or done, chances are other members also feel ill at ease.

Briefly review this section before each meeting to keep techniques for handling unproductive behaviors fresh in your mind.

Listed below are some situations and examples of what to do:

- **Monopolizer.** Interrupt the speaker with a summarizing statement and direct a question to someone else. For example, "That's very good, Allen. Now let's hear someone else's view on this, too." It may be necessary to interrupt: "Allen, I know this is something which is really important to you, but several others have thoughts they want to share. Van, what are your feelings on this topic?" You can suggest that the person has so much pent-up need to talk, that perhaps the member should make use of the *Lyme Disease Phone Support List*. If the monopolizer is difficult, solicit the group's help. If such tactics don't work, you may want to speak to the person after the session. Remember to be tactful.
- **Quick helper.** This person has the right answers but keeps others out. Tactfully interrupt this person by addressing a question to someone else. Be sure this person understands you appreciate the effort. Suggest, "Let's get several opinions."
- **Rambler.** When this person stops for breath, rephrase one of the statements and move on to the next person.
- **Arguer.** This person is trying to cause trouble; place this person in your "blind spot" right next to you. Pretend not to hear. Of course, recognize legitimate objection. Sometimes the group will take care of the persistent arguer.
- **Obstinate.** This is usually someone who does not see the point. Try to get others to help explain the point. Talk to this person after the meeting.
- **Wrong subject (Off track).** Direct attention to the topic being discussed. Say, "That is interesting, but I'd like to get us back on track."
- **"Gripes" about the leader.** Try to get another reliable member to talk to this person. Don't waste too much time on management gripes. Recognize legitimate criticisms.
- **Race, politics, religion, physician bashing.** Frankly state what you can or cannot discuss. Problems exist, but our work must be done.
- **Side conversationalist.** Side discussions are very distracting to the group. Pause and let others listen to the side conversation, or draw

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.

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

Another strategy is to plead ignorance in understanding the full set of circumstances and ask the member to adequately explain the problem. The more the person talks, the better the focus of the real problem.

In a group, the chances are good that you have been in a fellow member's situation. You might share this fact, but not at a time that will shift the focus of attention too much from her to you.

Once a group member realizes that he or she doesn't have to argue about being angry, or the right to be angry, then the "real" object or focus of this anger can receive the attention it deserves. Details can be discussed, and options for how the group member might deal with the problem presented. Other group members may share similar experiences, and depending on the skill level of the group and its leaders, there are various role playing exercises that can be tried. Such exercises can give the angry person a chance to view the situation and perhaps gain insight from different perspectives.

In some cases, anger gives way to a different emotion that the group member did not initially recognize. A frequent one is fear of what might or might not happen in the future. Others are guilt over something in the past; deep sadness over a realization; or difficulty accepting a loss. Thus, by being allowed to experience their anger, people can often move on to other feelings that may be difficult but important to deal with directly.

2. Displaced Anger

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

In the example of the angry wife she might be feeling angry at men in general these days, and could lash out at an innocent man in her group who has never even thought about being unfaithful to his wife. More often, the innocent group member unwittingly plays into the situation by having some of his or her own life situation evoked, and then takes personally what the angry one is saying.

In the present situation, the obvious example would be a man who has been unfaithful to his wife, and who has some strong feelings about extramarital affairs. He responds to the angry wife in the group in a way that might be less than objective and any discussion between two such people can then easily become an angry argument

in which each is using the other to express feelings that really belong elsewhere.

The best strategy for dealing with this kind of mutually displaced anger is to step in as an observer who cares for both parties and try to point out what you think is going on. Using what each person has said in prior group meetings, your goal is to convey that you don't blame them for feeling the way that they do, but it's not really each other they are angry at. On the other hand, be extremely careful not to accuse someone of displacing anger at someone in the group for something that has gone on in the group.

3. Anger About Something Inside the Group

Sometimes, especially in groups whose members get to know each other well over time or through contact outside the group, there's anger that is genuine between members of the group. This can occur when members disagree over the group or when someone in the group takes a strong dislike to the way someone else in the group is acting or being dealt with.

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

Ways to help angry members disagree fairly.

- **Clarify the issue.** What exactly is each person angry about? Can each person state clearly his or her own viewpoint and how it differs from the other person's? Sometimes a simple misinterpretation is the root of the problem.
- **Ask for the group's input.** If each party in an argument feels a degree of understanding from some people in the group, the intensity of anger may be reduced somewhat, as the person feels less threatened or alone.
- **Encourage "I" statements.** When I'm talking about how "I" feel or what "my" experience is (even when in response to something you said or did), you are less likely to be further angered than if I make statements about "you" and "your" behavior, passing judgement on you.
- **Allow people to finish statements.** People should be able to complete their thoughts, and not be interrupted by group members.
- **Keep discussions focused.** Don't allow side issues to be brought in unnecessarily and thereby complicate matters. Try to keep people talking about one issue at a time.
- **Encourage and model active listening.** Occasionally restate what each party is saying, or ask them to do it, to make sure people are hearing each other's messages.

- **Take a short break.** When things feel out of control, it may be useful to ask for a moment or two of silence, or perhaps to encourage a stretch, or a coffee break. This can give everyone a "cool-down" period.
- **Invite others to help out.** Sometimes, especially when things feel like they're at an impasse, it is helpful to get the feedback of others in the group who are not directly involved. Watch out for scapegoating, however, or for extremely uneven side taking. If this occurs, make sure someone speaks up for the underdog, or at least touches base with him or her. Example: "Well, it seems like a lot of people agree with John ... (to Mary) does that make you feel kind of alone?"
- **End the meeting with a round-robin.** Whether or not there is still anger in the air, it might be useful to give people a chance to have a last word about what happened during the meeting and about what they might want to see happen next time.

B. Underlying Anger

How can you tell when there is Underlying Anger? One clue would be its *persistence*, as in someone who seems to be angry all the time, meeting after meeting, and seems unable to accept repeated efforts to help. Another would be its *intensity*. When a person's angry responses consistently seem way out of proportion to the situation, it could be that the person is not really reacting to the immediate situation, but rather to a long history of circumstances that are simply beyond the reach of the group's help.

An important factor not to be overlooked is members' reactions to the person in question. If several group members share a concern about this individual, saying in essence that he or she seems "frightening", "out of touch with reality," or in some other way "not reachable", you have a good indication that the person's anger is threatening the group, and you should do something. An initial approach might be for the facilitator to speak to the angry person privately, and see if direct contact helps. How does the person react to that? Does the angry behavior in group change afterward? Is there an indication that continued efforts to help this person are worthwhile? If so, there are several strategies that might be tried.

One is to have the person come early to group a few times to talk about the situation with the core members or the leaders. This might help the person feel more cared for, or to feel more of a sense of belonging in the group. Another is to suggest that he or she not say anything in one or two meetings, but just observe how others interact. Individual coaching on how to follow the group's discussion might be useful along with some practice in active listening skills. *Sometimes a referral to a counselor is warranted as an adjunct to continued group membership.*

Obviously, if none of these suggestions work, then the serious question of continued attendance in the group comes up. Underlying anger can

be extremely destructive in LD Self-Help Groups, hurting both individuals and the group as a whole. It can frighten members away, cause others to feel like an "emotional punching bag", and can immobilize people to the point where normal group work is not getting done. Moreover, a person who has deep and unrelenting rage has probably been perceived that way by others, and has had major difficulties in other areas of life.

As much as people in the group might want to help such an unhappy individual, it may be that this person will not benefit from continued involvement in the group at this time, and should be asked to leave. As hard as that is to do, one must consider the needs of the group as a whole against the needs of a deeply angry person who appears unlikely to benefit from the group.

A request to leave should be made privately, with ample reasons given, and preferably with a referral to a professional counselor. This probably won't happen often, and it rarely feels like a good solution. Unfortunately, it is the only way to deal with this kind of anger while at the same time keeping your group intact.

III. BURNOUT

Burnout is the condition in which the stress and negatives of a situation outweigh the positives and continue to do so for a prolonged length of time without the hope for relief. Who "burns out"? Caring people who have entered a situation with hope and positive intentions.

Failure to support broad membership leadership development can result in burnout of designated leaders, especially if no clear and achievable definition of their role exists.

A. Symptoms of burnout

- Lack of energy and enthusiasm.
- Continuous low level of anger and frustration.
- Sense of futility and hopelessness.
- Lack of goals in life.
- Inability to do anything that makes one happy.
- Anxiety that never goes away and increases when you do certain activities.

B. Causes of burnout in group leaders

- Expanding role definition - doing everything yourself.
- Lack of achievable role definition.
- Lack of positive feedback - always leaving you to wonder if you're doing a good job.
- Isolation - not using the group for your own support.
- Failure to set limits - taking on others' problems as your responsibility.

C. Solutions to burnout

- Take periodic time off from anything stressful.
- Delegate responsibilities in the group and at home.
- Use other group leaders to discuss issues and for support.
- See a therapist - Advice from experts say that a few visits with a professional counselor can significantly help. Remember, all professional therapists see professional therapists!
- Return to the original facilitator function that is specific, reasonable, achievable, and time-limited.
- Recognition of one's own limits & family's patience.
- Meet your own survival needs by taking time for yourself and your family as priority *ahead* of the LD S-H Group.

IV. SUICIDE

Suicide is a difficult issue for anyone to discuss, especially laypeople. The group facilitator is under no specific obligation to do anything specific about someone who discusses suicide. However, if someone has a health crisis during the group meeting call for an ambulance and notify the person's family.

A. Items to consider regarding a potential suicide:

1. **Is the person giving away personal belongings?** This doesn't mean an item two sizes too small or out of style. Personal belongings would be the family's fine china, a wedding ring, etc. If so, the person may be carrying out a suicide plan. This is enough for you to move to action.
2. **Is the person making arrangements for affairs afterwards?** Is the person suddenly making a will, a trust for a family member or writing farewell letters to friends?
3. **Does the person tell you** that he or she is planning a suicide?
4. **Does the member have a plan?** People who move closer to a planned suicide must think about how to accomplish the suicide.
5. **How deadly is the plan?** If the plan seems serious, then you know you need to act immediately.

B. If the plan seems serious and deadly the facilitator/member should:

1. **Ask another member to come over** and help you talk with the suicidal person.
2. **Talk about options** that could help the person. This shows that he or she has something to wake up for tomorrow. Say, "Tomorrow I'll help you look for more information to help you."
3. **Show compassion** and don't say anything like "you won't do it." This may seem like a challenge to the distressed person.
4. **Have someone immediately call a relative**, the family doctor or

the local police (if there is no one else available). This person *must* be told about the potential suicide, asked to come *pickup* the suicidal person and take responsibility for seeing that the suicidal member gets help. Once you have done this, stop your involvement and let the family or doctor control the situation. Your continued involvement may interfere with appropriate medical treatment.

5. **You should follow through** with finding additional information and sending it to the person.
6. **Once the person has received professional help**, or presents a note from his or her doctor that the person can attend the group meeting, make the person feel welcome.

C. What to do after someone commits suicide:

1. **Remember, suicide is a personal choice.** You are not responsible for that choice.
2. **Suicide will leave a variety of negative feelings** in the group. It is best to have the group talk about feelings during the first meeting after the event. You should have a psychologist facilitate this meeting.
3. **Send condolences to the family.**

V. GROUP STRENGTHENING

All S-H Groups go through developmental stages, much like the stages in a person's life, from birth to maturity. As a group passes through these phases, situations may arise which may be disruptive. The following strategies and techniques have been developed in response to situations experienced by S-H groups.

Three areas of major concern to most S-H Groups: membership size, effectiveness of group meetings, and group leadership.

A. Membership Size

1. Group size decreases below 8 members at each meeting

Self-Help Groups that provide opportunity for discussion, such as LD S-H Groups, work best with 15 - 30 attendees. This allows all members to participate in sharing and discussion. It is a cause for concern when a group begins to lose its members.

There are many reasons why members may quit attending meetings. Groups all have a natural life-span and when members' needs are met, they may choose to drop out. Membership tends to fluctuate seasonally. Some people need to attend only one meeting to be reassured that their situation is not unique and that the group is available if they need it. Some people have unrealistic expectations, think the group will solve their problems, and then drop out when it doesn't.

The group will need to survey the members to determine why members are leaving. The LDF often hears from patients who attend a group meeting once, never to return. Why? They become too frightened and depressed by the message they hear that - physicians know nothing, Lyme disease suffering will continue throughout life, the disease is never curable, employers will fire you, insurance companies will never cover your medical costs, you can't get disability payments, your family will never understand, your marriage will fall apart, your body will fail you, and then you will die. If this was your first group meeting wouldn't you drop out?!

As you survey past members, start new publicity efforts to attract new members.

2. Group Size Increases to over 35 members at each meeting

If attendance is over 35 people per meeting you have a problem. There are probably two factors at work. First, you are probably providing an excellent service. Second, there is a real demand for a S-H Group.

A group with over 30 attendees will not be able to offer the depth of support that is needed. It is now time for your greatest leadership challenge - to start a second group. This may be under your leadership or the leadership of one of your trained co-facilitators & co-coordinators. Try to have a different meeting time for the second group.

B. Meetings: Effectiveness Decreases

The S-H Group's mission is to help people cope with their adversity. *Something is wrong* if members become increasingly dysfunctional or depressed.

Following are some situations which indicate a group's meetings could benefit from some first aid, along with some suggestions about what can be done.

1. Meetings become a complaint session. The facilitator or a group member can state his or her reaction to the way the meeting is going without blaming or criticizing. For example, "I'm feeling that a few of us are monopolizing the meeting with some pretty negative comments. Does anyone else feel this way?" A leader's reaction to the meeting can provide a model for members. However, all group members need to take responsibility for how a meeting is going and should not rely solely on the designated leader to keep things on track.

2. Group covering old ground, not moving on or progressing. Select a topic in advance and have each person look for experiences in his or her own life that relate to the topic. Also, do some reading as a group. Every member can read a book/article and discuss it. Or, one person can do a relevant reading and facilitate a discussion around it.

3. Conflict in the group. Stress positive points when addressing conflict directly. Keep expressing empathy as it is appropriate. Avoid accusing, blaming. Use "I" statements. Focus on how members are feeling now and what can be done in the future. Remind members how to practice Active Listening .

C. Stimulating Shared Leadership and Preventing Burnout

Every group has leaders, both in the formal sense where a person facilitates the meeting and in the informal sense whereby every person in the group takes on a leadership role by making suggestions, volunteering for responsibilities, keeping the group discussion moving or noticing when other members need special support. One way to develop the latter kind of leadership is to spread responsibility for group tasks among members.

VI. TERMINATING A GROUP

LD S-H Groups sometimes terminate. There are a wide variety of reasons: members recover, leadership burns-out or relapses, etc. It is important to separate the desires of the leadership from the needs of the group. If the group is still needed by the community, the Leadership should try a public search for a replacement. If the group no longer serves a purpose, then termination is the only option.

Loosening the bonds that tie a group together is a delicate task. Remember, the group may disband but the good feelings people have about each other and the good work they have done can continue.

The leader should do the following to help with the termination:

- A. Summarize the group's work together.**
- B. Express your own feelings.**
- C. Encourage group members to express what the experience has meant to them.** These feelings can range from happiness, sadness, relief, to a wonderful sense of accomplishment of a job well done.
- D. Try to heal any wounds that exist, if possible.**
- E. Celebrate, if that is the wish of the group.** A group celebration is often requested or required.

MEETING NOTES

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