

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 or other tick-spread disorders help themselves to recovery.
- **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. Group leaders will disclose group finances and corporate donations.
- **No member is to receive personal benefit** (fees, trips, etc.) for any information or referral made in connection with the group.
- **Groups recognize member privacy and 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.

"Many health and other personal problems have no easy remedies. Increasingly, however, people in need of emotional support for such problems are finding it in groups that are dedicated to helping people help themselves. For literally millions of people, these groups, called self-help groups, are providing an effective and rewarding alternative to coping with serious problems all alone. The essence of these groups is that their members help each other cope with or overcome a health or other problem that they all share."

C. Everett Koop, MD, ScD
Former Surgeon General
U.S. Public Health Service

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LYME DISEASE SELF-HELP GROUPS

MEMBER BROCHURE

You are not alone!

GROUP NAME:

CONTACT:

MEETING TIME:

MEETING SCHEDULE:

MEETING LOCATION:

LDF LYME DISEASE FOUNDATION

1 Financial Plaza, Hartford, CT 06103
860-525-2000 Hotline 800-886-LYME web: www.Lyme.org

WHY JOIN A SELF-HELP GROUP?

A Lyme disease (LD) self-help (S-H) group provides positive support when life seems to be falling apart. It is not a sign of weakness to join and attend meetings. Quite the contrary, joining a LD S-H Group is a positive sign of your ability to recognize your needs and take care of yourself.

LD S-H Groups provide four major benefits:

1. **Eliminating the isolation** felt by those affected by Lyme disease and *other* tick-spread disorders,
2. **Helping members** learn how to cope,
3. **Empowering members** with support and information so they can take back control over their life, and
4. **Assisting family** and friends of patients.

HOW IS A MEETING RUN?

Member Greeting - Members are welcomed.

Formal Opening - The meeting opens with a statement by the facilitator covering key concepts: the mission statement, disclosure of volunteerism and shared leadership.

Business - The facilitator announces the location of information table, donation jar, *LD Phone Support/Buddy List*, etc.

Discussion Topic - The facilitator or co-facilitator may start with a story about a personal Lyme disease struggle and how he or she found a new positive way to deal with the situation. Then, the discussion is opened to members. As time permits, the discussion will move to individual member problems.

Personal Discussion - Members have the right to use their first names only or stay anonymous. And, some members may just say "Pass" and say nothing. Usually several current members speak first. This gives new members an idea of how to consolidate their problems into a concise statement. Then, new members are given the opportunity to introduce themselves and briefly tell their "personal stories".

Formal Close - As the meeting closes the Facilitator or Coordinator will announce the time and place for the next meeting. The meeting will probably end on an upbeat note. You should feel better at the end of the meeting. If you leave feeling more depressed, please speak to the facilitator.

"I believe in Self-Help as an effective way of dealing with problems, stress, hardship, and pain ... Mending people, curing them, is no longer enough; it is only part of the total health care that most people require."

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ADDITIONAL INFORMATION

The leadership can have two or more positions.

This usually includes:

- **The Facilitator** - who runs the meeting and guides the discussion, and
- **The Coordinator** - who arranges the meeting details (e.g. time, location, copies of articles).

LD Phone Support/Buddy List

Members can develop a support network for use outside the meeting time by taking names and phone numbers from this list. Those signing this list have agreed to provide support to members between meetings. You are expected to honor the fact that this is confidential. Also, try to avoid late-night or early-morning calls.

Things 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 dealing with S-H issues.

- **Doctor bashing.** Discussing a health care provider by name is both nonproductive and slanderous.
- **Recommending medications** is practicing medicine without a license and could involve everyone in legal problems.
- **Political discussions.** Updating people on activities and events is appropriate. But, be careful! It is easy to move into the "black hole" of endless non-solutions. Worse yet, these discussions could seriously depress attendees.
- **Soliciting.** It is inappropriate for anyone, for any reason, to solicit from this group of sufferers. Anyone mentioning products or company names should be immediately excused from the group.

MEMBER GUIDELINES

There are guidelines for members in order to maximize the group experience. Members will:

- Recognize S-H are groups of people affected by LD or other tick-spread disorders, with a common bond of sharing our troubles, understanding, strength, wisdom and working toward recovery.
- Know that what is shared is confidential and that comments will not be repeated outside of the group.
- Have the right to remain anonymous.
- Listen, explore options, and express feelings without judging others.
- Have the opportunity to participate in discussion and the right to decline comment.
- Actively listen and avoid side conversations.
- Share the responsibility for making the group work.
- Recognize the need to help others. This can be by offering advice, serving as a co-leader, starting another group, or volunteering to conduct community education. However, this is not an obligation.
- Know that the decisions each person makes are one's own responsibility.
- Have the right to share their feelings. However, it is not O.K. to hurt people with their words.
- Try to help members feel comfortable.
- Will encourage positive comments and new viewpoints lest the conversation deteriorate into a "gripe" session.
- Try to recognize when a member's problems are beyond the group's ability to help and suggest the member seek professional assistance.
- Allow members to vent their feelings without taking their feelings personally; this often must be done before positive feedback can be given or received.
- Not wait until the last minutes of the meeting to bring-up a life trauma that has just happened. Even if a members has a major trauma, the meeting must still close on time.
- Be informed that if they need help outside the meeting time they can people listed on the *LD Phone Support/Buddy List*. The names and numbers on the list is to be kept strictly confidential.
- Always treat Self-Help Group Leaders with respect.