

by Nancy B. Smith

(This is a very helpful article on Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFIDS/ME) and Fibromyalgia (FM) support groups and how they can meet the needs of patients and their families. Anyone in a support group, looking for a group, or support group leaders will benefit from reading Nancy's thoughtful article.—Ed.)

There are many reasons support groups exist. They also have different styles and formats. Support groups exist so that people can reach out to each other and not feel so isolated. They are there to exchange medical and support information, and to keep patients active and encouraged. What many patients have not had is the luxury of thinking about the purpose, format and leadership style of the group, and whether these factors are suited to them. Many leaders are gradually recruited into the role or inherit the role from a previous leader. They too, have to ask themselves important questions to help the group thrive and to thrive themselves.

What Do I Want from a Support Group?

You need to ask yourself what you want from a group. The answer could be friends, general information, a place to be with others in a similar predicament, information on local doctors, the latest in medical treatments, answers to questions you can't ask anyone else, a place to vent your frustrations or be validated. Remember validation is important.

Don't overlook the fact that many support groups welcome family members. Having a family member as part of a support group accomplishes two things; it can help family members get information and a better understanding of this illness and it injects a healthy person into the group. Also, frustrations abound when the family status quo is tipped on its head as a family member gets ill and unable to fulfill the role he or she once did. That burden is often shifted, silently, and in some cases, with anger, from the patient to a healthy person. Support group meetings are a place where that is understood. This illness doesn't just affect the patient, it affects the patient's total support network.

You need to keep in mind these are self-help, mutual aid groups. People seeking support should try to be realistic in their expectations. There are some things that go beyond the limits of what a support group is able to offer, like spending a lot of time or attention on a particular individual's vast array of problems. If a person has a lot of personal issues to work through,

then perhaps professional counseling would be appropriate to address these in greater detail. A support group can allow people to bring up things that are troubling them, but it cannot take on the responsibility of solving their problems. The support group may be able to direct people to certain practitioners or institutions for help.

How Is a Support Group Born?

With a lot of labor pains and no spinal blocks! In many cases, a group of people dealing with the same issues will form a loose group, getting together to provide emotional support, to network and exchange information. Most often there is one person that seems to get things going. Eventually, it becomes a larger group and before you know it, a formal support group has been formed, with regular meeting times and locations. As groups grow, so do their functions. Many groups may go a step further by seeking ways to actively participate in community education—offering workshops, lectures and outreach efforts. Patient education is a major function of support groups.

As the group gathers steam and someone's living room no longer serves, the gathering place may be switched from a home to a hospital or church. This provides some stability, and in certain circumstances, lends credibility to the group. A hospital-sanctioned meeting makes for a better press release, but be aware that, on rare occasions, meetings might be attended by staff members who may monitor the kinds of topics being discussed and may even try to promote services offered at the facility.

How Does a Support Group Leader Evolve?

There are many answers to this question.

1. A person feels that s/he could do some good, sees a need and fills it, somewhat selflessly.
2. A person is looking for information for him or herself, ends up sharing with others and a group is born. Taking and giving is a good thing, especially when it is balanced. However, in life, nothing is perfectly balanced. So a warning for CFIDS/ME patients: Be aware of how much of yourself you give away. Watch yourself and don't over-do. However, do not protect yourself to the point where you don't do anything. Being totally selfish is only taking, and is just as unbalanced and unhealthy as being totally selfless. In this writer's experience, it is the balance between the two that is the goal.
3. The leadership position is arrived at by default. A person ends up as the leader, not by deliberate choice, but because no one else has stepped forward.
4. A person has leadership skills, can work well with others, delegates jobs and coordinates people. S/he takes the leadership role naturally.
5. A leader has stepped down and the next in line takes over, just to keep the group going.

In many cases, this works out well. Some-times it doesn't and the group falls apart.

6. An ego trip: Some people like the idea of being a leader, but in reality, their skills fall short.

What Is Involved in Running a Support Group?

The answer can be "a lot" or "a little". If you're interested, the Massachusetts CFIDS/ME & FM Association has information for starting a support group, and will be happy to help.

We'll start with "a little". A few people get together once a month at someone's house and exchange ideas, medical information, doctors' comments etc. At the least, it is a social hap-pening for a very ill and isolated person. It may look like nothing to someone healthy, but many times, just getting to that meeting means every-thing to the patient. And it has taken every-thing for her to get there. The experience of being at a meeting is validating, especially in a group of equals. Patients who have to interact with invalidating, dismissing and negative fam-ily members, as well as medical personnel, can find support groups a very helpful and necessary lifeline.

If the group is formal (never in dress code), it may put ads in the local newspaper and/or bring in speak-ers. At any meeting refreshments may be offered. This is only possible when there are enough volunteers to provide it (assuming the group has no money to foot the bill), the rules of the building allow food, and there is space to set it up. If it is the intention of the group to provide refreshments, it takes a lot of coordination and work.

Reminding CFIDS/ME and FM patients of meetings also seems to be a constant necessity. The group leader may call members prior to the meeting to remind them. This works well when the group is small, but as the group becomes larger, time and help become limited. One option is to create a telephone squad. The membership list is divided up and each person calls a few members. This works well to keep folks in touch with each other, but begins to unravel if a caller's list becomes too long.

"A lot": With growth come more needs and the call for more volunteers. The more people that help, the more you can accomplish. Some groups go to health fairs, hold seminars for medical personnel in their area, give lectures, work with the school system, conduct advocacy campaigns, hold raffles, coordinate with outside groups for interdisciplinary lectures, etc. Exhausted yet? Some groups have run medical conferences. These take work and money, but

the payoff is fantastic if just one doctor out there gets it!

Dealing with Burn-Out

Sometimes, when the group gets to be a lot of work and too much of an energy drain, support group leaders may find that leading the group has become too much, but they are reluctant to quit. It is at this point that tempers may become short and the leader may need to step back and reassess the situation. As leader, the question to ask is, "Do I still feel good about what I'm doing?" As long as the answer is yes, go for it. Again, members should be realistic in their expectations. A self-help support group is really supposed to be just that—a body of individuals who have come together for a purpose and ideally, are working together in achieving mutual goals. It may be helpful to spend a meeting discussing exactly what the objectives of this group will be and new members should be informed about these as they join the group. At least people would know what they could expect from this particular group.

Group leaders would be generally expected to supervise the main functions of a group, such as conducting the meetings, guiding the discussion, distributing information, being able to listen and receive feedback, and generally overseeing that the meeting is running as smoothly as possible.

These general functions should be broken down into numerous, individual duties and be shared by all the members. We recommend co-leaders wherever possible to help reduce the burden on volunteer leaders. Realistically, it becomes very hard for one person (the group leader) to take care of all the needs of the group by him/herself. No group should be dependent on "one" person. Members often tend to forget that the group leader is also sick and for some reason, it is common that members do not offer to help, even when asked. After a while, this will negatively impact the group leader.

However, when being the leader has become an onerous and stressful obligation, then it's time to re-evaluate the leadership role or scale back. There is a big difference between running a group by choice, and finding yourself trapped in the leader's role. Behavioral attitudes may be a clue if you are not sure what is happening to you. Do you find yourself avoiding group duties because you have "something better to do?" Do you resent time spent on group activities or preparation for meetings? Do you feel the group is interfering in your life rather than helping it? You may have "burn out." This attitude overflows into the meeting as the leader asks for but doesn't receive help. Growth of the group can falter as new attendees come away from such meetings with a bad impression, deciding not to return.

What Style Does the Group Present?

Is the group pre-organized, procedure-centered, and formal or does it tend to be free flowing, open and informal? Watch for your reactions to where the group is on these factors and try to find the group that is right for you. Or, if small changes could make the group work for you, stay with the group and, with respect and care-ful thought, make suggestions.

Size has a lot to do with determining how a group is run. A small group can handle one-on-one discussions more easily than a very large group, but such exchanges have the potential to slide into a "pity party." A pity party occurs when people sit around feeling sorry for themselves. It is not the same as everyone sharing information. A pity party has the potential to lead to depression and pull all members down. This is one outcome you want to avoid. Once in a great while, a support group leader has a "victim personality" and the group is run from this perspective. This group tends to disappear because people eventually stop coming. The majority of people who join a support group are not looking to be pulled down, but lifted. Small groups allow for more co-mingling among members. They are like a small family. As a group gets larger, the needs of the group expand and volunteers are sought out to meet those needs. In CFIDS/ME and FM many more people just stand back and take from a group than actively give to it. What makes self-help support-groups successful is the number of people giving. *If everybody gives a little, then every body gets something*

Insulation is another viable small-group style. It affords the CFIDS/ME or FM patient a place to go in order to escape the "world at large." The group doesn't really reach out into the community but offers an island oasis to its members. For a little while each month patients can be accepted with all their limitations, let their guard down and not have to be on top of "information." This style is an emotional support system in which members usually want to know only what pertains directly to them now.

Different Group Formats

The format of support groups should try to encompass two important areas—a forum for support and sharing and an educational function. Ideally, time should be balanced between these areas according to everyone's needs. But it is not always easy to maintain this balance and there will be groups that end up adapting to the needs of a select group of individuals—like the new patients only. Initially, this may seem noble, but there is a disadvantage. If the group has been functioning for a while, there will be a base of "older" members who no longer get anything from the meetings. Since they tend not to speak or share, they lose interest and stop attending. Then the leader is left handling the needs of the newcomers by herself or himself.

Old-member groups are run primarily for those patients who have considerable experience and knowledge of this illness. This format is good unless you are a new member. Then you will feel left out. How to balance the different needs of the old and new member is an ongoing dilemma. What some groups have done rather successfully is to start the meeting a half-hour earlier for new members only, so they are, in a way, debriefed. Handouts of printed material are available; thus, new members have something to read rather than remember. By the time the regular meeting starts, new members have a sense of what is going on. They may still have questions, but they don't feel completely left out.

The "all talk versus speaker" question is a common issue. Some groups want only speakers, and do not allow for discussion groups. These groups serve a very specific need and if your voice needs to be heard, then find a different group. If you constantly want to learn and hear from specialists, then this format may work for you. There is no law that says you can only belong to one group. You may have to join several to fulfill all your needs. Network and speak with many different people. Also, it is helpful to go to more than one meeting of the same group before making a final decision.

The "all talk" group works best if everyone sits in a circle. Usually each person speaks in turn and tells his or her story. This works well if everyone has a chance to speak. The group usually doesn't last if there are one or two people who monopolize the time. Many times, a leader will recognize this situation, but not necessarily have the means to handle it. Setting a time limit for each person is a good idea. Redundancy can become a serious problem, especially if there is a steady flow of newcomers speaking. A skillful leader can keep things moving along. The benefit of this format is that the person speaking finally has a place to be heard. This opportunity is very important to the member if s/he has been struggling for any length of time with invalidation from family members or doctors.

Another format is to have a "specific talk" forum. A particular topic or question is chosen for discussion. Ideally, each person offers his or her ideas. This generates original thinking, and doesn't put anyone in the position of having to tell her personal story. Sometimes such a session can get lively and last a lot longer than intended. Asking people to raise their hand to be recognized maintains some decorum and controls cross-talk. This works well in groups with more than 6-8 people. There will always be 1 or 2 people in a group, that when given the opportunity, will talk too much. Leaders, hone your skills! Knowing the difference between members that need to talk non-stop, and those that have something to say is important. Specific subjects, such as advocacy or disability, may hold a continuing interest for many members. If so, a person familiar with these issues may offer a short update at each meeting. Some groups make advocacy or disability their sole reason for being.

Many CFIDS/ME and FM patients are not able to comprehend the direct link between themselves as a patient, and the importance of research funding and advocacy. Some are cynical about government and politics and withdraw from such tasks. To some patients, this is a larger concept than they can't presently deal with; they just want the pain to stop. This is totally understandable. But, activism is an important motivating force for many support groups and their interest in such tasks is essential for progress against the disease. Think again whether you, as a patient, can do your part.

Time and Location

Time plays a big factor in support groups as well as location. If a meeting takes place in someone's home, it can be a relaxed format. If the group is meeting in a structured environment, perhaps a church or hospital meeting room, there may be strict limits on the amount of time the room is available. The average time for a support group meeting is normally 2 hours. After that, attention can flag. Many groups go for 2 1/2 to 3 hours. Much depends on the member's time and energy. When 4 or 5 friends get together for an afternoon in someone's home the time can go very quickly, while for 50 people sitting in an auditorium, 2 hours can seem interminable. When applicable, breaks can be scheduled and refreshments offered.

Speakers

The time allotted to the speaker is another area where there is choice. Some groups prefer to have the speaker for the entire meeting. Others will only allot the speaker half the meeting time, including discussion. If a speaker is volunteering his or her time to a group, it may be appropriate to offer the entire time to the speaker. Support group business can be handled quickly either at the beginning or at the end of the meeting. Keep in mind that meetings can rotate from a speaker one month, to a discussion group or specific topic the next. This model may be the best of both worlds. Whether patients need to talk among themselves or give all their attention to a speaker is dependent on the needs of the group and these needs may change with time.

Flexibility is required to keep a group viable. If the speaker opts for a question and answer period, it can be handled in one of 2 ways: questions taken from the audience by raised hands, or pre-written questions submitted to the speaker. This decision will depend on the size of the audience and the skill and comfort level of the speaker.

How to Handle New Patients

Have a packet of information to hand out. This system helps conserve time, eliminate repetition and gives the newcomer something to read, take home, and read again. When newcomers are asked to speak at the beginning of a meeting they may be afraid to say anything. It may be

better to run a group that will allow for some type of general discussion first, so by the time new people are asked to participate, they will have a better understanding of the topic. Getting newcomers involved later in the discussion may also help to decrease any self-conscious feelings they may have. This procedure also gives the older members a forum.

Assessing Your Group

In summary, there are many styles of leadership and formats possible for a group. However, when a group keeps losing members, it is important for the leader to ask why. Is it because there are members that feel left out, with their needs not addressed? Is it because the leader is the wrong person to be leading the group? Is the group not informative enough or lacking in any fun? Is it burn-out of the leader, a particular important member, or the group as a whole? Successful groups may have a number of active and knowledgeable members. If the group is large, and the physical setting allows it, smaller groups can be formed for specific topic discussions for a specified period of time.

Running a group is a chore done out of love. For whatever reason, the leaders give a lot of themselves, with usually little or no training in group work. Many support group leaders learn by trial and error. If a group fails, it can be helpful to figure out why, but it is best done without finger-pointing or blame, either of others, or of yourself.

Feeling Left Behind

This is a topic not often discussed. Sometimes valued members get better, move on in life, and leave the group. When someone moves on, she might not want reminders of the old times, or she is busy with new activities. Those left behind can feel abandoned. Feelings can be hurt. Promises made to keep in touch are often not kept, so insult is added to the injury of still being ill. If you are left behind, try to realize that the friendship was rooted in a shared illness, and must end when that is no longer held in common. Don't pine away. Reach out and try to give to the new people in the group.

If one of the group members is expressing excessive feelings of sadness and isolation, that member may be clinically depressed in addition to having CFIDS/ME or FM. Given the stigma of depression, many patients won't even consider this as a secondary problem. A person who has lost quality of life due to this illness has cause to be depressed. It is how the reaction is handled that makes a difference. There may be a biological imbalance beyond the control of the patient that can be easily treated. Leaders need to be alert to this situation because a serious depression of one member has the potential to pull the entire group down.

Support groups are the roots that nourish us. Initially many people were afraid to go to a meeting. When asked why, they usually said something like, "I don't know what I was afraid of." The unknown can be very scary, and the CFIDS/ME or FM patient is already handling a mysterious illness. Our hats are off to those leaders who persevere, trying to help, and to those group members who do whatever they can. Try to do whatever you can and the rewards will follow.