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Purpose of support group meetings

1. Emotional and social support
2. Provision of information on the illnesses, treatments, resources
3. Engagement in local community activity on illness issues
4. Connection with other CFIDS/ME and FM organizations and resources

The support group is a place to offer a safe non-judgmental environment in which patients, family and friends of patients and perhaps medical personnel can reach out to share their experiences, educate each other and share information such as which doctors are good versus bad.

Isolation is one big issue patients have. Support Groups serve a purpose to help end that feeling, as well as realizing there are others in the same position. Face-to-face communication is a good way to go. It helps because it is through understanding and being understood that experiences can be shared with the illnesses: how we obtained a diagnosis, successful ways of coping, treatments tried that have helped or not helped. Denial of being ill, frustration and anger are often attitudes seen in patients but usually, they all get along.

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Who wants to be a leader? Who makes a good leader? Who can be a good leader?

A Support Group Leader can be anyone who has reasonable knowledge or the desire to learn more and work together with others for mutual support and sharing. This person should have some facilitation skills and the ability to keep the group moving along with conversation, educational information and not let one person take over the meeting. The group should be steered towards the “helper therapy” approach which basically means people get help when they give help.

There needs to be a moderator for every meeting whose responsibility is to make sure the format is followed, that the meeting stays on track, that everyone who wants to, gets time to share, and that no one or several persons dominate the meeting. The job of the moderator is not to dominate the meeting either, just to insure that people are able to participate and that the various tasks of the meeting occur. The moderator's job does not have to be the Support Group Leader, but usually they are the ones to lead to group naturally. In a self-help group, the role of leadership is not limited to the support group leader, but the responsibility of the entire group. It is important to understand mutual support.

In most groups of people, usually one or two persons take the lead in making sure the group is formed and continues. This is natural. However, because the nature of the group is based on ill patients, it is important to build in duplication to reduce the burden on one person. Sharing the load is a watchword and prevents "leader burnout".

What

What are the goals of the group? What type of group do you want to run? Small and intimate, or large? What type of format will you follow?

Where

Where will you hold the group meetings? It can be anywhere from your living room to a church meeting room, public library, community center, medical office, or hospital. It is best if arrangements can be made with a medical or hospital facility. It adds a level of credibility to the illness. Hospitals usually run community calendars in the newspaper, so they will help with advertising. Seek facilities with parking or those on public transportation, and check if the meeting room is easy to reach and/or wheelchair accessible. The meetings should be held in a place that provides privacy and comfortable setting.

When

Decide when your group will meet. Will it be a weekend day or a week day? Day or night meeting? What time? How long? Weekend meetings gather a bit of a different crowd than week days or weeknights. Week nights can be difficult for folks who still work, but easier for those who may rely on a family member or friend to take them to the meeting. Weekends, folks want to rest. You decide when to meet and if the group needs a different schedule, and you have several people interested, you can always change the meeting time, providing the room is available. Weekends are usually not too busy in hospital meeting rooms. During the week, it

may be a bit harder to secure one. Ask around plus be sure to check on room capacity and whether there is any cost to use the room.

Decide how frequently you want to meet. Monthly meetings seem to be the best. Patients usually can not make 2 meetings in a month. It is also difficult to get everyone to come every month.

Patient meetings should almost always have a mandatory limit of 1 ½ to 2 hours, with a 5-10 minute break in the middle. Any longer and patients have reached their saturation point. A 1 ½ hour meeting might leave a little informal time at the end just for people to interact personally. However, if the meeting is in a home, the host's needs must be considered and there must be a rule that people not linger more than a set amount of time.

Group business such as setting up a phone tree for notification, or having someone send out email notices can be done either at the beginning or end of the meeting.

Why

Why do you want to be a leader? Is there a desperate need for a support group in your area and are you a natural born leader and fill the need? Do you need a social life and figure this is a way to go? If so, stop. That won't work. Your motives need to engage the group. No major egos allowed.

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- **How to Structure the Group**

Decide the structure of the group. It can be just for education, advocacy, discussion or a combination of these. Use the first meeting to discuss these options and decide in which direction the group wants to go.

- **Group Formats**

Usually patient support groups meet once a month, although some might meet twice a month. Formats can vary, but there are just a few general ones.

There are two major meeting formats:

1) personal sharing; and

2) the provision of information on the illnesses or illness-related activities. The information portion of a meeting can include sharing and discussion of illness topics: for instance a group discussion on current research trends, a category of treatments, which doctors have been found helpful, etc. Some groups will feature a speaker on a particular topic for either part of or the entire meeting time. It is advisable to reserve a little time after the speaker's presentation, so that folks can touch base with each other.

In the sharing portion of the meeting, the moderator/ Support Group Leader makes sure that everyone has a chance to share. If there is 45 min. allotted for sharing and there are ten people then each person gets 4-5 minutes. Each person who is trying to "get their story out" should not be interrupted, unless it is obvious that some information or remark could be of real help to them. "Cross-talk" or interruption should be kept to a minimum. However, an absolute prohibition of responding can prevent a valuable helpful word or tip.

- Group Leadership Responsibilities

It is important that the group leader be willing to have his/her contact information out in public, and available for folks to call. It is also very helpful between meetings for patients to be able to call or e-mail group members to build a personal support system. This, of course, is entirely voluntary and develops naturally between group members. Some group leaders will not share members' information, but the members can give out their information to each other. This helps build a network of friends.

The Support Group Leader maintains a group roster list. It is also helpful to have a sign-in sheet for each meeting. Many groups have a few volunteers do a phone tree or email meeting reminder notices so the burden of work is shared.

It is a good idea to start with shared responsibilities and set a precedent for job sharing. It is too easy to go it alone, do everything and burn-out. The group can be set up with co-leaders and/or rotating leaders

Maintain quality by listening to the group's wants and needs. This can be done by a formal questionnaire or by an informal discussion.

- **Group Evolution**

This topic involves the dynamics both of new and old support groups. New groups are somewhat more fluid as people get to know each other and work out group process. However, new groups should have sufficient structure so that meetings will be productive and meet the needs of members.

Groups that have been together for a period of time usually will have a more settled structure and format; there will be a core of longer-term regulars who will anchor the group and be responsible for responding to new members.

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There are several steps worth noting.

- **Name Tags**

It is worth noting that the cognitive skills patients possess may have brain interruptions. It is a good idea at each meeting to offer name tags for folks to wear. The removable labels can be

purchased at any office supply store. Use a sharpie for writing, otherwise, you can't see the name on the tag.

- **Handling New Members**

New members coming to the group will need some extra time to introduce themselves and their histories/issues/problems if they wish to speak. It is a good idea to introduce them, or have them introduce themselves at the beginning of the meeting so they feel included, even if they don't wish to speak at first. A little extra time should be allotted during the group meeting for a new member. However, such time should be reasonably limited, so as not to take too much time from the normal group format.

If possible, the Support Group leader can have a phone conversation with a new member before attendance at a meeting. This way, it serves as an introduction to the new member and as an orientation. Some new members may want to listen to everyone else first. Usually towards the end of the meeting, they realize they are not alone and feel more comfortable in speaking. Such prior discussion can help the new member and also minimize any disruption to the normal group process.

If there is an influx of new members, the Support group Leader may wish to hand out packets of information for them to read.

- **Seating Arrangement**

It is best if there is a large round or oval conference table, around which everyone could sit. Failing that put the chairs in a circle so people can face each other for better mutual interaction.

- **Group Turnover**

Normal group process involves turnover, both of ongoing group members and group leaders. Older group members will leave and new group members will come in. How the group works – relationships, priorities, expectations, and formats can change. But there are constants, which are the group purposes listed above.

- **Getting People Involved**

Ask people to help with certain tasks they might be interested in, whether small or large, but get them involved. Ask them privately so as not to create a high-pressure situation. Appreciate their involvement by thanking them publicly at meetings for a job well done.

- **Cost**

Try not to have a meeting where it will cost for the room. This is an all volunteer group. At the meeting, you can pass around an envelope labeled for donations, which help defer the cost of copying information for handouts and perhaps snacks. This way, patients can donate what they can. Don't flood folks with too many handouts. There is no fee to join the support group.

- **Advertising**

Can you put up notices in the building where the meeting will be held? Can you put a notice in the paper? Can you send a flier to physicians in the area? It works well if your meeting is in a medical facility and you get to know some doctors. The good reputation of the group will make doctors more comfortable in referring patients to your group. The group may want to partake of some local cable show or TV program. If so, individuals can make the decision if they want to go "public". Many patients prefer to remain anonymous.

If you are connected with a larger Association, will they advertise your meetings? Will they help your group get going? It is a good thing to belong to the Massachusetts CFIDS/ME & FM Association (MassCFIDS) — it is one of the oldest associations in the country.

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To be affiliated with MassCFIDS, NO selling of products or services is allowed at meetings. Speakers of all types are allowed to come share, but the groups are not a consumer group to be taken advantage of.

Pity parties are not allowed, so the leader must be able to handle a person on this psychological vent.

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