

## **Start Your Own Support Group... In 8 Easy Steps!**

### **1) Get Motivated.**

- Before a support group is developed, and most importantly continued, the support group “leader” must clarify their reasons for wanting to start up a group. It would be wonderful if there were thousands of support groups that reached every person with fibromyalgia, but a support group requires dedication, teamwork, and compassion, which can be challenging. Think of your own inspiration for starting a support group, because that is what will carry you through both the challenges and good times that occur with your group.

### **2) Form a Core Group.**

- Almost all support group leader offering advice concerning how a support group functions suggest having multiple group “leaders,” or a core group.
- Get 2-4 people together who are willing to put as much elbow grease in as you, and form the base of your group.
- Once you start expanding, the people in your core group can divide up meeting responsibilities, like a moderator, minutes and finance, hospitality, or other roles. Using the members’ strengths when assigning positions can be very helpful.
- Unfortunately, fibromyalgia can have an effect on how much time and effort a core member can contribute to the group. Remember that every group member faces the similar challenges with FM at some time or another. Make sure everyone is familiar with each other’s responsibilities so any absence will not disrupt the flow of the group.

### **3) Find a Location.**

- A central location like a library, civic center, hospital, church, or health center is usually good for support groups. Hospital conference room space can be competitive, and usually a member of the group has to be part of a church’s congregation to use the facility. Once again, use your resources, and go for what is best for you, your group, and your community.
- When it comes to meeting time, there is no way to accommodate everyone in the group. Evening meetings usually work best for those who are employed during the day, but sometimes people don’t like to drive at night. Try to work around this by carpooling or possibly having weekend meetings. Generally, support groups meet once a month, on an assigned day to prevent confusion (i.e., the last Thursday of every month).

### **4) Get a Sponsor.**

- Usually the word “sponsor” relates to finances, but in this case you want to get a “power” sponsor. This is a physician, nurse, or someone who works with fibromyalgia patients who can bring credibility to your group. For example, if you have a physician who treats FM patients, they can help refer patients to your group, speak at meetings, and give you more authority if you start fundraising or educational events in the future.
- It may take time to get a sponsor, so only propose the idea to someone you know and who believes in the idea of a support group. Don’t expect the person to put much time into your

group unless they offer it to you. Think of the core group and members as the cake, and your power sponsor to be the icing – it's not essential, but it sure makes it taste better!

### **5) Bring in Members.**

- Make business cards with your contact information on it. Often people learn about support groups through a spontaneous meeting or casual conversation. Websites such as VistaPrint and others offer affordable pricing. Have everybody in your group carry some of these business cards around. If you have an established meeting time, date and place, list that on the card. If you are still just meeting for dinner once a month or haven't built up your group, list your contact information on the card along with the support group's name.
- Make flyers to hang in public areas you think would be good advertisement. Always ask for permission before posting anything.
- Let health professionals you work with know that you are bringing fibromyalgia patients together for information and discussion sessions. Suggest leaving a flyer in their lobby.
- The power of word of mouth is very strong. Use it to your best ability.
- Post your group contact and meeting information on the National Fibromyalgia & Chronic Pain Association's website. Thousands of people will see your group on their support group directory that already displays over 100 groups nationwide!

### **6) Your First Meeting.**

- Depending on the number of participants in your group, your first official meeting may be a small dinner at a core member's home or a gathering at a hospital conference room. By now you have probably had many get-togethers with your core members as other participants have slowly trickled in. Remember to move your group to bigger and more convenient locations slowly while keeping in mind the comfort and needs of the group. Five people in a large conference room is probably not the most comfortable situation.
- Encourage members to make themselves comfortable by sitting, standing, fidgeting, or whatever is necessary. Let them know it is okay to leave if they need to, and that everyone else in the room understands their situation.
- If you have plenty of participants and are ready to have a larger meeting, make sure all the "official" business of the group has been established. Assign your core member responsibilities, have a group name (or possible choices for a name to have the members vote on) and a mission statement. Prepare materials to give out to the members (described below) so the members are welcomed. This way you can be organized and official, but not overpowering to the members. Present yourselves as organized, but as regular members of the group.
- After your group has grown, or once you have the capabilities, put together a new member packet to give to each new attendee. Include your group mission statement, group rules, contact information, meeting calendar, newsletter, helpful articles, a flier, and business cards. Have your members put the information in a folder to bring to each meeting.

### **7) Expand Your Resources.**

- Keep all of the information pertaining to your group in a "community folder." All contact information, articles, handouts from speakers, meeting minutes, and finances should be kept in a binder that is accessible at each meeting.
- Members often bring suggestions to the group, including treatments that have worked for them, interesting articles, or which doctors have been helpful to them. Open discussion is

always encouraged, but before an article is given out or added to the community folder, make sure it is from a legitimate source and permission to copy it has been obtained.

- To your members emphasize the importance of promoting your group to the public. Have them share it with their doctors, and ask them if they would like to speak at your meeting about a certain topic. Do the same for their massage therapist, acupuncturist, tai chi instructor, water therapy instructor, and others who would like to share their resources with fibromyalgia and chronic pain patients.
- Many fibromyalgia and chronic pain support groups also act as support groups for CFIDS, Lupus, MS, and other chronic pain and fatigue illnesses. Consider advertising to a wider audience. With so many patients having overlapping conditions, bringing a more diverse group of people can give members greater perspective.
- The National Fibromyalgia & Chronic Pain Association publishes a magazine, e-newsletter, brochures, and several other educational materials for public use. In most situations, with a small donation to cover shipping and handling costs the NFMCPA can provide these materials for you to make available to your members. Citing the NFMCPA as your resource, feel free to reprint articles from the web.

### **8) Keep It Going.**

- If you are having both discussions and speakers, make sure to alternate them to keep meetings interesting. Always allow a question and answer as well as a discussion time after a guest speaker has made their presentation. Use other meetings as round table discussions, but make sure you are organized and keep things moving so everyone can share their thoughts while following group rules.
- Many times support groups are challenged by slow periods, bad health, or other circumstances that may interrupt the meeting dates. Even when times are hard, always try your best to hold the meetings even if it is two or three people having a discussion. For many people their support group is one of the few stable events in their life, which is why you need to have a meeting every month and avoid canceling. This is why you have co-leaders: the group depends on all of you, not just one.
- The size, intensity of activity, and accessible resources of your group will determine what you can do in the future. Consider a yearly calendar, newsletter, and event planning in your area. You will find that once you get several people together with a common goal the possibilities are endless!

**The National Fibromyalgia & Chronic Pain Association wishes you the best of luck!**

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