



Setting up a Peer Support Group

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What is Peer Support?

The principles and benefits of peer support

“Peer support means receiving support and understanding from someone who’s equal, had similar (not necessarily the same) experience and insights” (Peer2Peer Steering Group)

Understanding the role of peer support group

We are all social beings by nature – connectedness and community are necessary, if not vital to our well-being. Through their very existence, social relationships can be a source of healing for many.

Throughout the world, patients have used their own experiences with fibromyalgia, and other conditions, to create a wide variety of self-help and advocacy groups, frequently called support groups, peer support groups, peer-run services, or alternative services. The self-help movement grew out of the idea that individuals who have faced, endured, overcome adversity, experienced similar problems, life situations, or crisis can effectively provide support, encouragement, and hope to one another.

Peer support can play an important role for people living with fibromyalgia. People need a lot of support because pain and medications can change the way they think, feel and behave. In addition to the necessary support from a doctor, peer support can really help someone coping with the physical, mental and mood changes of fibromyalgia.

Peer support can help reduce depression and fear. It can help you understand what is happening to your body and to develop positive ways to deal with emotions and changes. Peer members of the group who have already been living with fibromyalgia can be good advisors. They “have been there” and can empathize and relate. Peer support breaks down isolation and helps to link people to needed resources.



These groups also offer emotional support, friendship, individual advocacy, information, perpetuate a sense of belonging, and a way to improve the system.

As the name implies, peer support groups are peer-run, they are small and voluntary, and they accomplish their goals through mutual aid. Peer support groups offer the opportunity to bring both personal and social change, and to find solutions with the help of others. People living with fibromyalgia can offer each other support based on first-hand experiences with issues such as medication, over-medication, social security disability, housing, employment, human services agencies, neglect and families and friends.

Bear in mind that the advice/suggestions offered by peers shall not be a substitute for professional, medical, nor healthcare advice. It is strongly encouraged that members always consult with their healthcare provider regarding their medical care and treatments.

Currently, there is a critical shortage of peer support groups for people living with fibromyalgia in Canada. More and more people are getting diagnosed and the need for support will grow. A peer support group is one way to get advice and information to help you positively live with the disease.

The effectiveness of peer support groups

These groups have worked because they are beneficial to all involved. For years, people have known that the mutual-aid relationships formed within peer support groups enhance their personal wellbeing. People have continually found the groups help them in many areas of their lives:

- The act of joining together with others who have “walked in their shoes” enables individuals to recognize that they are not alone, that other people have had similar experiences and feelings. Individuals living with fibromyalgia often do not have the support of family and friends. Peer support groups can provide the sup-



port that may be missing from these other systems.

- Peer support groups offer a safe place for self-disclosure.
- Peer support groups encourage personal responsibility and control over one's own treatment. Because group members are actively helping each other, they gain a sense of their own competence.
- In contrast to the professional/client relationships, members of peer support groups are equals.

After years of listening to patients say how peer support groups have helped them, professionals have also recognized the effectiveness of peer support groups. In a landmark report on mental health (can also apply to fibromyalgia and any other conditions) issued by the Surgeon General, a section was devoted to self-help groups:

As the number and variety of self-help groups has grown, so too has social science research on their benefit. In general, participation in self-help groups has been found to lessen feelings of isolation, increase practical knowledge, and sustain coping efforts. Similarly, for people with schizophrenia or other mental illnesses, participation in self-help groups increases knowledge and enhances coping. Various orientations include replacing self-defeating thoughts and actions with wellness-promoting activities, improved vocational involvement, social support and shared problem solving. Such orientations are thought to contribute greatly to increased coping, empowerment, and realistic hope for the future (U.S. Surgeon General, 289).

Peer Support means walking the same road together, helping each other out along the way.



The benefits of peer support

People involved in peer support groups often state that their involvement allowed them to “find their voice” or helped them in general. Some key benefits are:

Emotional Support: This is the benefit most often identified when individuals are asked what they received from a group. Peer support has the potential to benefit helpers and not just “helpees”. Peers who help others talk about how rewarding it is to “give back,” how it is helpful in their own recovery/management, and how it increases their sense of confidence and competence in connecting with others.

Sharing information and advice: Groups provide a safe place to express what we are experiencing and feeling. Being encouraged by somebody who can say “I tried it and it worked” has a different impact from advice from a professional.

Increased social network and friendship: Peer support can give people a sense of being part of a community. This often happens through opportunities for being heard and understood, identification with others, having the experience of being valued and cared for, and also making friends. Peer support has the potential to create a sense of increased social connection and reduced isolation. Members are not alone. They are part of a group; part of a family.

Becoming empowered: The capacity to stand up for oneself and/or others is at the core of most self-help and peer support groups. Peer support has the potential to transform powerlessness through helping others, take on meaningful group roles, and provide encouragement to see one’s strengths and resources.

Finding hope or positive role models: With peer support, hope is something that develops within the group, rather than created by the group. Peer support provides chances for members to serve as role models for other group members. It can be very powerful when group members share their journey with others who are feeling hopeless or discouraged.



Achieving insight: Insight occurs when group members discover something important about themselves – about their actions, what motivates them, and things kept hidden inside.

Learning coping skills: Developing coping skills in peer support groups are based on shared experience and expertise – “This is how I coped.” Coping generally involves practical strategies for managing situations.

Reduced symptoms: The successes of other types of peer - support initiatives can be measured in terms of symptom relief, recovery time, life expectancy, functioning, and psychological well - being. People living with fibromyalgia can definitely benefit from reduced symptoms.





Principles of peer support

Mutuality – Coming together sharing a common ground where you both give and receive support

Equality – Being viewed and treated equally, knowing that your story is as important as anyone else's

Trust & Respect – Having a trusting relationship where others respect and accept you for who you are. A relationship where you are not judged or undermined

Hope/Recovery – Inspiring hope and a belief of a positive future by focusing on the positives, your achievements and for what you have or will overcome

Shared Experience and Knowledge – Sharing your journey, experiences and your knowledge to help others

Empathy – Being among others who can put themselves in your shoes, someone you can relate to, who really does understand



Peer Support can help you if you are being affected by

- Stress & Anxiety
- Anger
- Depression
- Physical Health Conditions
- Loneliness & Social Isolation
- Stigma

Or if you simply need someone to talk to



How does a peer group differ from a therapy group?

A peer group is not a substitute for a therapy group. A therapy group is led by a professional therapist who is trained to guide people through difficult emotional issues. A peer-led group is usually led by someone who is not professionally trained, but who has knowledge of the issues at hand, and some skills in leading the group. People can often find emotional support that is therapeutic and helpful in a peer support group.

A **peer support group** is a safe place to discuss:

- treatment options, treatment side effects
- stigma and discrimination
- harm reduction
- feelings of isolation
- depression
- physical, mental health and addictions issues
- coping mechanisms
- disclosure
- the capacity to heal mentally, physically and spiritually
- educational and prevention information and support service referrals





Steps to establishing and developing your own support group

Even before the meetings begin, starting a self-help group takes a lot of time and energy. A group can be started on the front steps of a church, in the back of a coffee shop, in someone's living room or even virtually. You don't need a license or permission to start a group; all you need is the desire and the initial idea. There are, however, key elements that need to be addressed when it comes to the beginnings of any group:

Why do you want to start a peer support group?

It is important to understand why you want to start a support group. Is it to get your own needs met, or is it to help yourself as well as others? You want to make sure your own needs do get met, but you can't let them get in the way of keeping the group going. You have to be able to put your issues to one side for the benefit of the entire group.

You need to ask yourself:

- Am I biased in any way?
- Am I open to talk about any topic?
- Can I accept all members regardless of their background?

Consider why you are starting the group and who you wish to help. Think ahead to what the outcome will be for your group and whether it will be short or long term.

You may already have expertise that you can utilize or you may need to seek training or involvement from a professional with lived experience?

You need to be honest with yourself if you want your support group to succeed.

**“Just be honest with yourself.
That opens the door.”**

Vernon Howard



Research

After you have made the decision to start a peer support group for fibromyalgia, your next step is to do your homework.

Before you begin organizing your own group, find out what groups exist in your area. There may be a local group that can meet your needs, and often, these groups love to help groups who are trying to get off the ground. There may be regional, provincial or national groups that you can affiliate with to gain expertise and resources. These groups can provide proven, workable models for the development of your own group.

You should define a target audience. You might want to include family members or friends or you might want your group to remain made up solely of people living with fibromyalgia; you might want a certain age group to attend; you might want people who are trying to survive in the workforce; you might want to include anybody and everybody who considers themselves to be a person with fibromyalgia. You should decide while you are planning your group.

You can look to professional organizations to help identify and reach your audience.

It does not need to be complicated.

Once you have determined the need for a group in your area, you may want to enlist help from others who share your interest to help you get started.



Develop a project plan

Now that you know why you want to start a peer support group, and have done your research, the next step is to develop a project plan.

Several questions should be addressed as you develop a project plan. You might begin by asking yourself the following questions:

- What is the purpose of this group?

- Who are we trying to reach?

- How will we recruit participants?

- How will we work with other available services?

- Where will we meet?

The answers to these questions will make up your project plan. This plan will grow as your membership grows and people add ideas and expertise.





Different models of peer support

Peer Support is not a 1 size fits all system, therefore, peer support comes in many different forms

You need to identify the model of your peer support group.

Almost all peer support group meetings have an educational component and provide some emotional support, but how you define and set up your group will set the tone for the type of group you envision.

Here are some different types of support groups:

Self-help Groups (*Drop-in Meetings*)

A self-help group means coming together with others so you can support each other by sharing experiences, knowledge, practical help and have people to talk to who can give you emotional support.

Self-help groups are important for people who need to receive emotional support and education especially during a time of crisis.

People who attend these meetings may also be seeking to learn more about community resources and information about other types of meetings and support groups.

Exploring all aspects of fibromyalgia in this type of group helps people to really connect with other people living with fibromyalgia.

Peer Education (*Informational [Educational] Meetings*)

This will be someone who has their own experience using their knowledge and training to educate others.

This group is for people who want to learn more about fibromyalgia in general or a specific topic.

This format suits people who want to educate themselves and meet other people living with fibromyalgia but who may not be comfortable talking about very personal issues with others. Even



though the main focus is educational, such groups also provide an element of emotional support as there are others attending the meeting with similar interests, fears and questions who may share personal experiences or feelings.

Online Support Groups

An online support group can be anything from a group/forum on Facebook to a moderated online community. If you find meeting others in person overwhelming, have difficulty in social situations or meeting new people, this offers you an opportunity to still benefit from the support of others. Virtual support groups can be self-help, educational or both. Virtual can also include structured courses and peer mentoring.

Structured Courses/Programs

Structured courses bring together a group of people with a common difficulty and a common goal. A structured course will be facilitated, which could be a professional, who will educate the group on a specific topic whilst providing useful practical tips and exercises.

Peer Mentoring

Peer mentoring means being supported one to one by someone who can use and share their own experiences, knowledge, difficulties and successes to help you.





Why, What, When, Where, Who, How?

Ok, you have already figured out the *Why* – and the *What* – the next steps are to set a date and time and find a place for your first meeting, whether that be in person or online. In addition to determining when your first meeting should be held, how often and for how long, decide where the group will meet. You will need to select a meeting place well in advance (2 to 4 weeks) of your first meeting in order to give you time to publicize the meeting.

If meeting in person, you may also want to consider your meeting place when selecting a time. Is the area unsafe in the evenings if you chose to have an evening meeting? How safe are the parking lot and the building itself? How late does public transportation run?

Finding a place/Setting

Deciding where your meetings will take place is a very important decision. People must feel safe and comfortable.

A suitable environment is important to a successful group. Your meeting place should be neutral, comfortable, accessible, quiet, confidential and appropriate in size for the group. It should also have good lighting and ventilation. People must feel safe and comfortable.

Comfortable chairs are important as people living with fibromyalgia can have fatigue, muscles and joint pain. Seating can be theatre/classroom for informational groups (you can also use a U format), or in a circle format for emotional support groups.

The room should be easy to access with no cumbersome stairs or heavy doors and be relatively private where you will not be disturbed. Choose a room that does not feel “institutional.” The room should be close to a restroom.

Also, select a room large enough to show a video or film, or to accommodate a guest speaker.



Try to find a meeting place that is close to public transit with available parking, if possible, has accessibility to people with physical disabilities, is in a central location and easy to find.

Places of worship, schools, community centres, community health centres or other public buildings often allow community groups to use their facilities. Ask other local groups where they hold their meetings.

While many of these buildings offer space to community groups for free of charge; nevertheless, to develop a good relationship with your host organization, it is a good idea to pay rent. Even a little money collected by the group will help to establish your good name. One of the purposes of paying rent is to prove that you are both a reliable organization and that you will respect the space and your host's requests. To help you in securing a consistent time, always remember to leave the room cleaner than when you found it. Along with paying rent, this act of responsibility will help to earn respect and support from your host organization.

If you are supporting someone 1-to-1, consider where you will meet.

Once you know what buildings are available to your group, you can select one that best meets the needs of your particular group.

A final important point to keep in mind when selecting a place is to find somewhere that you can meet on a regular basis. It is hard to have regular meetings when you can't rely on a consistent schedule.



Frequency & Duration

Now that you know where the group will meet, how will you identify how often you would like to meet and for how long (this may be influenced by your venue).

Some groups meet every week, others every couple of weeks and others meet once a month. How much time and energy are *you* willing to give to your peer support group? Will you have someone helping you organize the meetings?

It is recommended that your meeting does not exceed 60 to 90 minutes (120 minutes max.) or people may get fatigued. Don't forget, they still need to get home.

Roles and Responsibilities

Depending on the model of your peer support group, identify responsibilities and responsible persons who you might ask to help with those responsibilities.

Facilitator: What are the qualities of a facilitator? Good listener; shows care and compassion for people on their journey of acceptance; and comfortable managing group dynamics.

- Recommend 2 facilitators, with potential rotation depending on capacity
- Patients may be at different points on their journey of acceptance, which may lead to a few voices taking up space or derailing the conversation

Consider your role, do you want to be responsible for continually arranging and facilitating the group? Would you like the group to be self-led? Do you wish to appoint a different group leader? Do you intend on recruiting a professional person to lead the group or run a structured course?

Another potential member role is “greeter” to help new members feel welcomed.



Advertising

How are you going to tell people about your peer support group? Cost effective advertisement is important and may not be as hard as you think.

- Word of mouth is a great way of letting people know about your peer support network so be sure to talk about it. You can also approach local support providers, social services and community groups to spread the word.
A way to reach people immediately is by speaking in public. Attend conferences, speeches, or other presentations aimed at people with disabilities and advocates. Ask the speaker if you can announce the formation of a self-help group before or after the presentation. Have interested people come up to you after the meeting and have them give you their names, phone numbers and/or email address.
- You may want to consider creating a simple flyer or leaflet. Think of high footfall areas where you can place your leaflet for free such as the library, supermarket community boards or local newspaper.
- Social media and social networking are easy way to communicate with people. Any person can set up their own page on various sites for free. One suggestion that has been recommended from peer members is to have your page/group “closed” so that what is discussed there remains there. With a closed group, there is less fear family, friends or employers will find out about your members’ struggles.



Costs

When starting up a Peer Support Group, consider the costs of the group which may include renting a venue, advertisement and refreshments. First, look to reduce costs wherever possible; you can approach venues for free space or host your group in the community. Those who attend may be happy to contribute a small amount to cover any overhead, be sure to consider other options.

It is important to always be transparent when dealing with money. Be vigilant, keep accurate records and be open to scrutiny.

Training

Consider whether additional training would benefit your peer support group. This may mean accessing a course yourself or exploring options for a professional to become involved in your group. You can also look to utilize various free programs, guides, booklets, etc.

Encourage and engage interest in the support group by stating what will be covered and the benefits of support. Clearly state times, date and location of the meetings.

Boundaries and Code of Conduct

Setting ground rules for a support group

Ground rules must be developed and agreed to by all members in the group. It is one of the most important steps to take before the first meeting. Ground rules help to make sure meetings are not chaotic and help members feel safe enough to talk about personal issues or offer advice to others. Draft a ground rule list and discuss reasons for the ground rules. Members may have additional rules or changes to the ones you suggest, so ask members to comment to ensure you include what is important to everyone. After a discussion of the rules, they should be adopted by all members of the group. If group members take part in building the ground rules, they are more likely to follow them later. You may wish to put this in writing, or cite this at the beginning of each group to set the tone.



Common ground rules include:

- **Confidentiality** will be important to some members. What steps can you take to make your group as confidential as possible?
- Remind people about confidentiality at each meeting. What is said in the room stays in the room.
- Inviting members to share during check-in about if or how they want to be acknowledged outside of the meeting space. Some members may prefer to remain anonymous outside of the meeting.
- **Respect:** Show respect for other members with differing views.
- **Aggressive behaviour:** Problems such as a person disrupting the group, talking too much or becoming overly familiar can happen, you will need ground rules in place about how to deal with a disruptive person.
- **Punctuality:** Arrive on time.
- **Doctor bashing:** Don't let people go on at length about problems with their doctors; it can make other members feel uneasy about their own treatment.
- **Civility:** Give everyone a chance to speak, to be heard and to be supported. Don't interrupt or monopolize the conversation.
- **Keep discussion in the first person:** Always use "I" or "me" statements.
- **Negativity:** Try not to focus only on the negative



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Membership in the group

Now that you know where and when the group will meet, how will you determine who will join?

Group size: The size of the group will depend on the type of group you want to start, the size of the meeting room, support group members expectations and the goal of the support group.

For an *emotional group*, you may want to limit the size to six (6) to ten (10). Having too many members will make the experience impersonal and it will be hard to meet member's expectations to have the time to talk about their issues and having their needs met.

For an *informational meeting* it may be beneficial to have a larger size since members are there to learn more about fibromyalgia in general and specific topics from a speaker rather than from other group members.

Recruitment: Create an ad or flyer that clearly and concisely explains what the group is about and its format. State whether the group will be open or closed, time-limited or ongoing.



Role of family and friends in a peer-run support group

The idea behind a peer support group for patients is that the patients should make the rules. These groups provide a haven to which patients may go to seek the support they are lacking in the “outside world.” Family and friends might want to help, but the support that comes from other patients is the driving force behind

the effectiveness of many self-help groups. As you are starting a group, you might consider including family members, but there are risks to that involvement. While there are family members and friends who are supportive and considerate, there are also members who feel that a patient is a burden and who will not support him or her. This relationship between patients and unsupportive family members or friends would not allow the peer support group to thrive. You can lead such friends and family members to groups that have been started by family members for family members (if any exist in your area).

Role of professional in a peer-run support group

While the role of professionals in a peer-support group is something that has been debated, many patients feel that professionals have no place in such a group other than as a funding source. The professional who truly believes in patient empowerment can be of considerable assistance in getting a group started. The professional's role should evolve from one of greater to lesser importance – ideally to total disengagement. The professional could be “on call” in case the group wants outside assistance, but the professional should wait for an invitation to get involved.





How to facilitate your first meeting

By the time you have scheduled your first meeting, make sure that you have a general idea and purpose of the meeting.

One of the members should stand at the door and “meet and greet” newcomers.

The purpose of the first meeting is for group members to:

- Get acquainted
- Clarify personal goals and group goals
- Learn the procedures to be used in the group, such as ground rules
- Learn how the group will function and how to get the most from the experience
- Discuss confidentiality and limits of confidentiality

Once everyone has arrived, you may want to ask the group members to state the possible purposes and goals of the group and what their expectations are. Explain that the group is designed to meet the needs of its members so their input will determine the goals as well.

At the start of the meeting, brainstorming can begin. Use a blackboard or easel to write down what members hope to gain from the group. At future meetings the group can develop an “action plan” to work on achieving these goals.

The first meeting allows people to have a clear understanding of the group goals and group interactions.

Planning ahead

Try to stick to your original agenda but be flexible and allow members to speak freely. Discuss future meetings. Who will decide on an agenda? How will the meeting be run? Establish ground rules and let new group members know that they are welcome in the planning process. Discuss the agenda for the next meeting and divide tasks, such as bringing refreshments, among willing members (if you are offering this option and the venue allows).



Leading the discussion

After allowing time for comments and feedback, ask group members if they would like to share some information about themselves. You may want to begin this process in order to make newcomers comfortable and encourage them to share their own experiences. Encourage new members to share, but don't pressure them. Make sure that all members have an opportunity to speak if they wish.

The opening speaker should talk longer than other speakers, this will set the standard of how the speeches should go for the rest of the meeting. When the floor is open to other participants, remind everyone to let the person talk. There should be no interrupting, there should be no comments, and there should be no advice given unless asked for. Let people finish their thoughts so that everyone has a chance to speak their mind without interruption.

Before the meeting is over, pass around a contact sheet to obtain names, numbers and/or email address of new group members. Make sure that group members have the name and number of a contact person. Establish when and where your group will meet in the future. Discuss the availability of group members to determine how often the group should meet. During your first group meeting, try not to get bogged down with organizational details, these can be addressed in the future meetings. Thank everyone for coming and invite them to stay for refreshments, if provided.

Beverages and food (optional, also depending on your venue)

Sharing food is a very good way to help members feel more comfortable and can help people with food issues (hard time cooking or eating, poor appetite). Having water available to drink is very important.





Ideas for future meetings

If you plan on bringing new ideas and perspectives to the meetings, adding variety is an excellent means to do so. Variety will simply alter the routine – instead of having a string of meetings that seem to be the same.

There are many ways to add to your group's dynamics. A speaker can come to talk about topics both related and unrelated to those which you have been covering in your group meetings. Speakers do not have to cost money; local organizations, stores, or community centres might have suggestions as to finding a speaker, or they themselves might have someone who would come and speak to your group.

Providing educational materials enables people to make a wide variety of decisions about their health, as an active participant in their health care. If you do provide educational information, be sure it is reliable and up-to-date. If you are giving people information sheets, etc., with links to internet sites, remember that not everyone has access to the internet, or knows how to use it.

Authors or poets are also good speakers and they might present a more unconventional talk. Authors might read from their books, and poets could hold a poetry session where members of your group could also share things that they, themselves, have written. These speakers might present a different perspective.



Having a session on advocacy would be a constructive way to hold a meeting. The result of leading a workshop would be a better understanding of how patients can advocate for themselves. This skill is imperative in our society and learning this skill in a peer support/advocacy group is a perfect way to spend a meeting. After learning these skills, your group can hold a letter-writing meeting which will allow group members to use their self-advocacy skills.

A movie/video night would be a way to incorporate ideas talked about in previous meetings, or a way to construct other topics for future meetings. Looking at the way other members in society look at the peer support group movement would be a great way to start a dialog. Watching the movie (or part of it) at the beginning of the meeting could lead to a good discussion.

Overcoming common problems

Most groups experience problems at times and peer support groups are no different. The following are risks and challenges for peer support groups:

Leadership burnout can be caused by trying to do too much and by being overloaded by painful stories. It can occur from the high demands of coordinating, recruiting, and maintaining the vision and, in some cases, from being a public figure.

Irregular attendance or low membership are some of the most common complaints with support groups. They can threaten the existence of a group and also have the potential to leave remaining group members feeling further isolated.

Dominating or controlling members may talk more than their fair share, talk over people, yell or talk loudly, put others down, or try to tell others what to do, think or say. Behaviours of such members can be particularly challenging for groups that lack an identified group leader.

Silent moments, a completely silent moment, dealing with incorrect information, inappropriate jokes, anger, crying and side talk all pose challenges to the facilitator and to the group.



Take heart that trouble is generally infrequent. Here are some facilitator tips for overcoming problems with group dynamics:

Refer to the ground rules when appropriate. Ground rules should help you avoid or handle most of the problems that can occur

Have the group develop and agree to new ground rules if a situation regularly occurs that isn't covered by your original set. If you must interrupt or challenge a member, try using a calm and reassuring voice in a non-threatening manner. Always try to reassure the person with a positive comment when interrupting or when refocusing the group.

Talk about how we are affected in a personal way by these behaviours, and say that being honest, sensitive, caring and respectful of others is of utmost importance.

Remember that the entire group is responsible for maintaining the harmony of the support group – not just the facilitator.

Sample support group format

The first order of business – each member should check-in with the group. The members usually talk about any important issues that have come up since the last meeting, or just a general “where they are at.” This allows all members to speak and is important for establishing group unity. The check-in for each member is usually two to three minutes, but should not last longer than five minutes. During the check-in, group members may ask for additional time to talk about topics or problems they would like to discuss with the entire group. The member checking in should not be interrupted with questions or comments.

The peer facilitator may also introduce a question into the general check-in such as: “When you check-in, please describe how you are feeling.” (Encourage members to go beyond using “Fine” or other one-word description.) “When you check-in, please tell us one thing that you feel good about or grateful for.” It helps group members to start out with a positive instead of a negative comment. This can also be used for the check-out.

The second part of the meeting is ideal for discussing a wide range of



topics. It is important to talk about various topics and to have the group prioritize and set an agenda for topics that should be discussed at each meeting. You may want to arrange for a speaker to come to the group.

It is important that each member be able to bring closure to the group meeting. Allow about five to ten minutes at the end of the meeting for the members to check-out. This is the time for members to have a final word or thought. This could be a simple goodnight or a comment about the meeting. The person checking out should be allowed to talk without interruption. The ending of the group is an important time for giving the members a positive feeling about group unity and hope for the future.



A few final words

As your peer support group grows, you can gain influence by networking with other groups. Fibromyalgia Association Canada (FAC) can put you in touch with other local groups or other resources through its website.

Starting a peer support advocacy group for people living with fibromyalgia is not an easy process, but it can be a rewarding one. The information on these pages is meant to serve as a starting point. Keep in mind that once the group is off the ground, the responsibility to keep the group going does not lie solely with one person – every member of the group must take responsibility for the progress of the group. Don't be discouraged if your first attempt at starting a group is unsuccessful.

If you cannot find enough interest in your area to develop a group, go back to your original research. Seek out other groups in the area that you can join or seek advice from. The individuals that showed interest in the group might want to join you in another type of project.

Consider an online support group. The Internet is a great resource for information on consumer issues. It also allows you to meet consumers from all over the world. The bottom line is stay involved. Remember that having people with lived experience involved ensures that people with fibromyalgia will have a voice in fibromyalgia policy. Don't let someone speak for you!

