SUPPORT GROUP LEADER GUIDE

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1   Introduction

It can be incredibly isolating to live with a rare disease like Primary Sclerosing Cholangitis. Personal connections with other PSCers and their caregivers can be some of the most critical sources of support as we navigate life with PSC. Local support groups can provide a continuation of the connections formed at our [Annual Conferences for Patients and Caregivers](#), or as a way to meet other community members. As a general description, the Merriam-Webster Dictionary defines a support group as, "a group of people with common experiences and concerns who provide emotional and moral support for one another."

If you think there is a need for a local support group in your area, we encourage you to start one! The support group can take whatever form you wish: it can range from a casual get together every few months, to more regular, structured meetings to discuss substantive research updates and the realities of living life with PSC. The key is to make the support group your own, and to personalize the nature of the group to suit everyone's needs.

It is important to note that local support groups are not endorsed by PSC Partners Seeking a Cure. PSC Partners Seeking a Cure accepts no responsibility for any information, activities or costs associated with local support groups, nor is PSC Partners intending to provide an endorsement of such group. Any information or advice provided in a local support group does not constitute medical or legal advice, and should not be relied upon as such. Before making any medical decisions, always check with your doctor.

This Support Group Leader Guide addresses several considerations that may be helpful as you begin to think about starting your own support group. Feel free to follow whatever approach best suits the needs of your group.

2   What Makes a Good Support Group/Group Leader

As we know from experience, having PSC is a scary journey where one may feel alone, that others (including medical practitioners) often don't understand what the person with PSC (PSCer) is going through (e.g., "you don't look sick"), or what the caregiver is experiencing (e.g., not knowing how to respond, a hesitancy in mentioning their own concerns). Local support groups are a valuable resource in helping one another through this journey.

Living with a chronic illness can be emotionally and financially draining. It can take a person and his or her loved ones out of what was previously their comfort zone, their everyday life. In addition, for many with PSC, the expression "you can't judge a book by its cover" clearly applies. Often, the PSCer's outward appearance gives no indication of what is occurring on the inside: the scarring of the bile ducts, right upper quadrant pain, etc. In this way, the disease may be "invisible" to others, and its seriousness not understood. Further, because PSC is an invisible illness, too often friends and others may tell the person with PSC that he or she does not look sick, or that he or she looks great. While such statements may not be intended to cause harm, the PSCer may be left with a feeling of not being believed and this can lead to changes in self-image and self-esteem, and a feeling of loneliness and isolation.

What makes a good support group and a good support group leader? We believe it is a person who cares about others, a person who "gets it", and a person who has the ability to listen, and help others in dealing with an awful, often debilitating disease still awaiting a cure. Groups may start off with one involved and committed person serving a leadership role and grow to form a local PSC community where additional group members become involved in group operation. Group co-leaders help ensure the group works effectively and share both the workload and the sense of commitment to the group.

Through the sharing of knowledge, feelings, and experiences, PSCers and their caregivers learn from each other and take comfort in knowing they are not alone. Support groups provide patients, family members, and others impacted by this disease a regular opportunity to meet in person. They are member-focused and patient-driven. They provide a venue for discussing and validating the person's needs and feelings, an environment that is non-judgmental, and one that is interested in providing both support and accurate information. Support groups acknowledge the importance of respecting and maintaining confidentiality and help fill gaps between national efforts and on-line support groups.

We believe an important strength of a support group is that it remains adaptable, that as a PSCer's needs change so might the person's participation in the group. The informality allows the group to remain welcoming to those with PSC and others affected by this disease. At the same time, it is important to keep in mind that the support group is not intended to, nor implied to be a substitute for professional medical advice, or to be used for medical diagnosis or treatment. The support group can serve, however, as a valuable resource, as it can offer education and support to PSC patients, families and caregivers within a designated area, and can provide information about future events and activities. Our belief is that each group identifies its own focus area, and that this may change at various times. Your group may wish to focus solely on supporting those with PSC and their caregivers, to help one another deal with the quirkiness and difficulties of this disease. It may wish to host information sessions on PSC, or social activities. Support groups have the opportunity to help not only those affected by this disease, but also to inform and educate others, including medical practitioners on the impacts of PSC on those affected; e.g., on the constant itch that scratching does not stop. Your group may begin with one purpose, but will have the flexibility to adapt based on the changing interests of its members.

In this document, you will find a variety of topic areas for those who are interested in establishing or further developing a local support group. We have tried to provide the information in a manner where the segments both flow logically and are easily identifiable. In addition, other areas of PSC Partners website (www.pscpartners.org) have information that may be helpful, e.g., our literature site, Conference(s) information, and our Patient Registry.

A special note in regards to 'pediatric support groups'. In addition to the material discussed in these guidelines, support groups for "pediatric pscers" may want to focus on the families of persons with PSC going on outings/doing activities together. Bowling, a pizza party, picnic at a park, etc., may provide a safe environment for support and possible conversations. A child/young adult with PSC may benefit more from a specific activity with others similarly affected than from meeting in a more formal group setting. Parents of a child with PSC may also want to consider forming their own local support group to share common areas of concern/interest.

We are excited for your interest in helping those affected by this disease and wish you much success in your endeavors. We invite you to contact us at contactus@pscpartners.org. to share your interest and learn more about the work of PSC Partners. In addition, if you are interested, we can arrange for you to talk with one of our local support group ambassadors on these guidelines.

Note: In preparing this document, information was used from the PSC Partners Seeking a Cure website. In addition, the Dystonia Medical Research Foundation's Support Group Manual was used as a source document as well as the Pulmonary Fibrosis Foundation Support Group Leader Guide and information from members of our PSC Partners community. You can review all references in the Additional Resources section.

3 Three Critical Mandates – Confidentiality; Record Keeping; No Medical Advice

Confidentiality is of primary importance for support groups, and we strongly suggest that this be carried forward as a policy in all group activities. Information that might individually identify a group member should not be released outside the group. This expectation should be stated at the beginning of each meeting, along with any other expectation for that particular meeting (e.g., meeting format). A good rule of thumb is: "What goes on in the meeting stays in the meeting."

> Any news release about a group activity that includes a picture or name should be done only with a signed news release permission form signed by the competent adult.

Record keeping is another important aspect of support group operation. As a general comment, it is suggested that the local group establish and maintain a consolidated internal document (e.g., folder) on the group itself, containing information relating to the group's formation, meeting locations, meeting dates and general topic areas. This folder also might include a list of resources, membership, and other information to provide a history of the group and its operation that can be shared with future group leaders and members. As with other documents that have individually identifiable information, this material should be maintained in such a manner as to protect the individual's confidentiality. While it is unclear how often this might occur, such safeguards help to protect the person against inappropriate contacts by pharmaceuticals or other similar entities.

The third mandate is not to give medical advice to another group member. Encourage group members to consult with their personal medical practitioners on questions about the person's specific medical condition. While group leaders/members may share their personal experience with medical care, this is not, nor should it be a substitute for advice from a medical professional.

4 Organizing, Developing, and Maintaining a Support Group

Organizing any endeavor from scratch can feel a little overwhelming at times. Our suggestion is to take it one step at a time. Each group is different and there is no "one-size for all". In your early planning, consider some basic questions – e.g., what is your objective, and what steps are needed to achieve that objective? Below is information we believe may be helpful.

4.1   Support Group Purpose – Tentative Determination

During the formation of the group it is good to identify the expected group purpose. The purpose can be refined after initial group members are identified. Some topics/questions that may arise during this process:

- A further conversation on the reasons to start a support group, such as providing support, offering companionship, and helping one another in learning how to cope with lost health and independence.
- Reaching out to medical resources for their guidance on issues of interest for PSCers and their caregivers and on strategies for dealing with these issues.
- Increasing awareness about PSC in the medical and lay communities.

4.2   Identifying Participants

Identify others who share your desire to form a support group. In addition to forming a leadership team, you can provide support for one another and co-contribute to the growth of the group. Possible resources include friends, family, medical practitioners, community representatives, etc.

Hepatologists and gastroenterologists may be willing to inform their PSC patients of your support group and provide contact information. You may want to prepare a handout/flyer with your group's contact information that medical practitioners can share with their patients. PSC Partners Seeking a Cure should not be mentioned on the handout/flyer. These same practitioners may be willing to speak with your support group. (See the section on Meeting Type - Speaker for further information.) In addition, there may be other credible healthcare providers (e.g., physical therapists, nursing staff) who can serve as valuable resources.

It is good to remember in both the developmental and later stages that not everyone is interested in attending a traditional support group; however, those persons could have other interests, such as attending guest speaker presentations, making a donation/fundraising, distributing information, etc. The "umbrella" of the support group may be as wide or as narrow as the local group desires.

4.3   Initial Planning Meeting

Upon identifying other interested persons, an initial meeting is suggested to allow attendees to get to know one another and to discuss shared interest areas, as well as how they see the group operating, and the skills and assets they can contribute. In the best of worlds, the meeting may lend itself to an initial division of tasks, for example, determining meeting location and agenda setting; how meeting notifications will occur, whether refreshments should be served, the use of name tags, etc. Discussion topics might include: group objectives and what is needed to achieve those objectives, and the resources that may be available.

4.4   Physical Surroundings

The physical surroundings are important. It is important for attention to be given to such details as room temperature, comfortable chairs, and quiet surroundings, as well as outside lighting, parking and safety. Attention to such basic details can have an important impact on those attending the meetings and their commitment to the group. Similarly, seating arrangements are

important. Arranging chairs in a circle makes it more likely that all members will see each other and thus be more likely to participate. At the same time, classroom style seating may be better when there is a formal speaker presentation.

As suggested earlier, support groups for children/young adults may want to take the form of outings/activities where conversations can be more organic and less formal.

4.5 Communicating – It's Important

Effective communication is important for establishing and maintaining a viable support group. For groups newly formed, some viable contacts include relevant and credible medical practitioners in the area (e.g., doctors and hospital staff) and distributing flyers to such places as churches, physical therapy centers, and libraries, as well as placing notices in the newspaper and on-line community calendars.

It is important to have a system in place to respond to contacts and share information. Some methods for keeping others informed include, but are not limited to, e-mail lists (including use of the "bcc" line for those who wish to keep their address private). Another method can include mailings (e.g., a mailing list, periodically updated). It is suggested that the support group establish a "contact address" that may be used by group members and others interested in getting more information on the group.

All communication should be undertaken with an awareness of the need to maintain confidentiality at all times and to never provide medical advice to group members.

4.6 Developing and Maintaining the Local Support Group

Support groups have the opportunity to grow with a stable and committed membership. From a leadership perspective, it is important to make sure no one person dominates early discussions and that any possible personality conflicts are immediately resolved. To help the group move forward, it is important to ensure that strong and committed personalities have a role in the group that is supportive of their interests. Establishing such a leadership core (including co-leaders) helps to ensure such persons stay involved and contribute to the growth of the support group. Other valuable tools may include continuing to recruit (on-going process); doing a year-in-review to identify strengths, areas for improvement, accomplishments, etc.; discussing with group members their future interests with respect to the group; communicating with group leaders in other areas to see "what works".

4.7 Leadership

Leadership styles differ and what works in one situation may not work in a second. For example, an authoritative leader may not be effective in working to achieve compromise. There is no one single, all-encompassing style of leadership and, for this reason, multiple group members serving leadership roles are valuable. An effective group is aware of the strengths of its members and uses each of these as appropriate. This is another strong argument in favor of having group co-leaders whenever possible.

In a related context, the group leader's (co-leader's) demeanor (e.g., mood and personality) can have a significant impact. A leader who is cheerful, approachable, and enthusiastic helps to

create a warm and supportive atmosphere, one that can encourage others to act in a similar, productive manner.

4.8   Publicity

At some point, you may want to consider sharing information about your group. For example, getting the word out about meetings can help attract new group members. Placing meeting notices and public service announcements through local newspapers, social media, community bulletin boards, radio stations, and other credible means can increase the profile of your support group. These support groups are independent groups, so PSC Partners Seeking a Cure's name or logo may not be included.

4.9   Group Development

Effective support groups rely on the positive efforts of members to achieve and maintain the group's objective – e.g., to educate and support. Other needs are being met when members get the meeting started, arrange for speakers, help keep the meeting moving, give information, or summarize events.

By nature, support groups operate in an informal manner, most appropriately with a leader and co-leader(s), and other members who help in a variety of areas. This sharing of responsibilities can help the group become and remain strong. Examples of involvement might include setting up the meeting area, fostering heightened awareness and education, distributing pamphlets relating to PSC and those affected by it (patients, caregivers, etc.) and others.

Informal groups often are effective in helping meet emotional and physical needs. Informal groups may, at times, become more formal, e.g., getting outside speakers on areas of interest, and on undertaking specific tasks. One PSC related outside resource is PSC Partners' mentor – mentee program. This program operates year- round and matches up, ordinarily, newly diagnosed persons with PSC and/or their caregivers, with a person who has been dealing with PSC for some time. For further information, see www.pscpartners.org or call 303-771-5227.

4.10 Setting an Agenda

For efficiency, it is suggested the support group calendar be set 6 to 12 months in advance to provide time for gathering group member input, assessing whether a committee should be appointed to set the agenda; identifying date/time/group location, making sure to the extent possible it does not conflict with religious holidays, major sporting events, etc.; planning seasonal activities; and creating an on-line method for gathering suggestions.

4.11 Preventing Burnout

No matter the dedication and sense of commitment one may have, there is always the risk of experiencing "burnout". For example, you have been leading the support group for a long time and you are just plain tired! To be an effective source of support for others, you must first take care of yourself. Some steps that can address this are further delegation of responsibilities, turning over some duties to the group co-leader, and stepping back and taking a break.

5   Group Leader Considerations

Running a support group can be both challenging and rewarding. As a support group leader, it is important to be able to show such skills as being knowledgeable, a good listener, a good organizer, non-judgmental, and capable of managing difficult personalities. These are in addition to continuing your general efforts to keep the group viable.

To effectively fulfill these roles, it is important for a group leader to be aware both of his/her strengths and areas to strengthen. Do not hesitate to ask others for help or work to delegate responsibility among interested persons. It is strongly suggested that whenever possible, the group works as a team, using the strengths of the members to move forward.

Most support groups are more informal in nature. The group leader is looked to for providing orderly, pleasant meetings, encouraging others to participate, and recognizing that people come and go as their interests and needs are met. An effective leader wants to make those attending feel welcomed. In such groups an "open door" policy for participants is often beneficial.

5.1   Meeting Location/Time

When possible, it is suggested group meetings be held in the same location, preferably a conference room at a hospital, public library, academic setting, or similar location. Your hepatologist, gastroenterologist, or other medical practitioner (e.g., a hospital social worker) may be able to help identify possible meeting areas. Meeting in members' homes is not recommended as this can lead to difficulty in remembering where a meeting is taking place, directions, etc.

As you choose a location, please keep in mind such factors as security issues (e.g., lighting, convenient parking), bathroom and other accessibility issues. Meeting times (e.g., in the evening, during the day, on weekends) should be done with a consideration of the make-up of the group (e.g., concern over driving at night). Similarly, meeting frequency can be determined in part on the group composition. Generally, it is recommended that groups meet on a monthly or quarterly basis (which may help reduce the possibility of burnout), for one or two hours. Setting this time parameter allows some assurance for topic coverage and provides attendees an expectation of meeting length. Of course, it can be adjusted later as warranted.

5.2   Operation of the Support Group

A successful support group is one where group members feel accepted and able to receive and to offer support with respect to the topics/concerns that arise. Sharing individual experiences and ways for dealing with situations often can be as beneficial as hearing a presentation by a mental health professional.

It also is important to strive for group cohesion, particularly with respect to promoting interactions between old and new group members. For example, a person who has been successful in dealing with a particular PSC-related issue can offer support to a new member on ways to manage the issue of concern. A benefit to older members is that their interactions with newer members can serve as a reminder as to why they originally joined the group. In addition, this sharing can help participants feel better about themselves and the group.

As a general comment, groups may fluctuate in the number of members at any given time. While an assessment of such situations can be helpful, it is important to avoid getting discouraged if the group dwindles in size. It is very important to continue with meetings. Some participants may need to know the group will last before they wish to commit more time and energy.

One important aspect is to keep current on credible articles and other credible information relating to PSC. It may be valuable to use a small portion of each meeting to discuss current event issues/articles. Doing this may also serve as a means to identify possible topics for future meetings. You may find the PSC Partners website a helpful resource for keeping aware of current information.

Another resource that may prove helpful for group operation and management includes providing group members with a calendar of events (with specific dates when possible) and asking individual members to share their experiences as the basis for an article, provided this is done in a general, non-identifiable manner. As a general comment, some helpful tools, when used appropriately, are the use of humor, cartoons, positive statements that allows the reader to come away with a good feeling. One of the objectives for this type activity is to help keep the group functioning and viable.

6   Group Meetings and Pre-Meeting Preparation

A main objective of a support group meeting is that it be responsive to the needs and expectations of its members. One way to help achieve this is to have various members of the group fill different roles during a meeting, especially where others express an interest in being more involved. This can strengthen a person's commitment to the process, as well as develop a core group of involved members. One example: have one person greet new members and introduce them to the group. Another tool to enhance responsiveness is to provide an opportunity for feedback, via e-mail, and/or within the group setting, and/or through general, non-identifiable suggestion sheets. This may ask for such information as areas of interest (speakers, topics, etc.), areas of concern (problems, issues, etc.), and/or general comments and suggestions. You may want to request the commenter's contact information or decide that this is not necessary.

A third approach is to remember the importance of the use of constructive humor. This can help lessen group sadness, while strengthening group bonding and providing the opportunity for an effective discussion among group members. For example, one common "irritant" is when a caregiver (often family member) asks the person with PSC, "What is your pain level today?" The group may choose to discuss their "responses" to such frequent questions, as well as ways to educate the caregiver that it would be greatly preferred if this question was not constantly asked.

Another important trait is staying organized to ensure meetings run smoothly. Methods to help achieve this include advance preparation for the meeting, drafting a meeting agenda, arriving early the day of the meeting, and using meeting checklists. An example of an inclusive pre-meeting checklist might include such areas as speaker/program decided, with AV needs and introduction prepared several weeks prior; the advance (2 weeks) distribution of flyers/meeting notices; obtaining needed materials (e.g., poster) two weeks in advance; arranging for refreshments in advance, with these set up one hour prior to the meeting; having signs identifying meeting location; and notifying the front desk of meeting, if applicable. At the

presentation, the leader/host welcomes everyone, and if seen as appropriate, does a go-around where people introduce themselves. The meeting should begin and end on time, allowing for Q&As. If felt suitable, the speaker might be given a small gift of appreciation or later send a thank you letter.

As noted above, it is important that group meetings be reflective of group member interest. This can cover a variety of options, ranging from a discussion of what has been occurring in the lives of group members to a more structured, topic-oriented program. Other points might include thanking everyone for coming, mentioning upcoming topics, and mentioning when the next meeting is and its focus. If possible, a general summary and assessment of the meeting should be prepared and filed, including such areas as comfort, space, etc.

These programs can be as expansive as the interest of the group members. In addition to topics identified by the local group, the PSC Partners website may be helpful in identifying possible topics and resource material. In addition, you may want to look at the section Meeting Type – Topic Oriented for more information.

Unforeseen events can occur at the last minute, thus affecting the planned support group meeting. For example, speakers may need to cancel without advanced notice. To manage this issue, it is suggested that the group leader(s) maintain an alternate list of topics to discuss.

As a general suggestion, if you have space, you may want to have general information on PSC, such as brochures, available on a table at the meeting site. You can get these from the PSC Partners website at http://pscpartners.org/brochures/.

7   Suggestions for Effective Meetings

Developing some basic rules can help ensure an environment where group members feel comfortable attending the meeting and sharing their thoughts. These rules can be drafted by the group leader with input from group members and can be posted at every meeting. New members should be made aware of the rules. In addition, any group member should have the option of opening up any of the rules for modification. Below are suggestions that may be helpful in running an effective meeting.

7.1   For the Group Leaders

- For consistency, schedule meetings on a regular date at the same location.
- Create a friendly, safe, and cooperating atmosphere; strive to ensure that neither ideas nor people feel belittled, nor feel pressured to participate.
- Point out that judgmental comments by group members are not appropriate, as the desire is to establish an encouraging, supportive, non-judgmental environment.
- Assist new members, helping them to feel part of the group.
- Work to ensure that interruptions of a group member's comments are kept to a minimum, and that all members of the group are respected.
- In introductory comments, set out a few of the guiding group principles - e.g., confidentiality; encouraging participation; reminding the group that "what you say here stays here" but

acknowledging any limitations on this (e.g., expressing intent to do harm to self or others); and initiating/inviting an initial topic(s) for discussion.
- Strive to allow the group to use the abilities of all members.
- Help the group and its members to adjust to changing needs and situations.
- Share leadership. Where possible, identify a person/persons to serve as co-leaders.
- Keep members well informed and up-to-date.
- Help ensure decision-making is done in a consensus-building manner.
- Ensure that group members (as well as group leaders) do not provide medical advice to others.

Group leaders should regularly share their expectations with the group. These expectations are based on mutual respect and include such areas as the following.

7.2   For the Group Participants

- Keeping confidential what is shared by group members within the group.
- Listening, respecting, appreciating the comments of others, and speaking honestly in response to comments.
- Reaching out to new members to help them become part of the group; whenever possible, introduce yourself to persons attending their first meeting, thanking them for coming.
- Being open to the comments of others in the group.
- Minimizing giving advice to others.
- Allowing everyone the opportunity to speak, and taking care not to dominate the discussion,
- Realizing and accepting that each participant may be in a different place in their struggle.
- Avoiding judgmental comments.
- Respecting the group and its members by arriving on time, turning off your cell phone, and staying throughout the meeting.
- Helping the group maintain a focus on the topic at hand, avoiding veering into non-relevant topics (e.g., political discourse).

Three "disclaimers" – (1) Avoid medical diagnosis; instead encourage group members to consult with their personal medical practitioners on questions about the person's specific medical condition. In addition, (2) group members should be reminded that information shared in group meetings does not necessarily reflect the viewpoint of the support group leader(s), or the setting where the meetings are taking place. (3) On occasion industry professionals may try to attend meetings for inappropriate "mining" of support group members. This should be discouraged.

8   Suggested Meeting Format

As general information, it is suggested that meetings start at the scheduled time. Holding a meeting up for late arrival can be seen as showing disrespect for those who did arrive on time. The group leader ordinarily would welcome people to the meeting, and ask them to wear their name tags for easier identification. New members are introduced and, as with all meetings, the basic meeting rules are discussed, including confidentiality. The group leader may want to ask each member to spend 2-3 minutes discussing occurrences in their life since the last meeting.

Old, unresolved topics might be updated, and then the focus can turn to the agenda for that night's meeting.

8.1 Ensuring Participation

Maintaining a supportive and focused group discussion can be a difficult task for any support group leader. In addition to members who might spin off a discussion topic, there may be others who try to dominate the discussion or stifle the involvement of others. The group leader has to continually assess, and often re-balance what is occurring. This is needed to keep the desired focus and to make sure all members have the opportunity to participate and to feel "safe" in doing so. At the same time, it also is important to consider that not all group members know how to appropriately participate in a support group discussion. This section and the ones that follow are intended to help foster group discussions.

Group discussion may be impacted by the number of people involved. Topic oriented programs (e.g., outside speakers) may have a significant number of attendees. However, the best size for personal (open group) discussion is between six – eight (recommended not to exceed ten members). This number allows for a sharing of experiences, with all having the opportunity to contribute. Where there are more than eight members, consideration can be given to breaking out into two or more groups, with the groups coming back together at the end of the meeting with a member of each group reporting on his or her session. A later section covers Meeting Type – Open

As with any group, at times, certain individuals may try to monopolize or take the conversation into uncomfortable areas. It is important that the leader be on the lookout for these situations and develops strategies to address such situations. Techniques that may be helpful in steering the conversation or moving it along includes: opening up discussions; broadening or limiting participation; assessing what is occurring within the group, and redirecting as appropriate; helping the group to reach a decision on a group issue; and providing feedback and lending continuity to the discussion.

8.2 During the Meeting

When desired participation is not occurring, the group leader/co-leader should invite other members into the conversation. This may also be a supportive sign to others in the group. One approach to encourage a conversation is to ask open-ended questions – those that cannot be answered by a simple yes or no. Later sections provide two examples – Framing Questions and Frequently Asked Questions.

Other helpful strategies include maintaining eye contact and offering support for others to join in the conversation. One example is specifically asking another group member for his or her thoughts on a given comment. Another approach is to give support to a person who is having problems participating, perhaps saying, "This must be very difficult for you to…" (Note: at the same time, the person should not be pressured to respond, and if he or she chooses not to respond, their decision should be respected).

8.3 Closing the Meeting

Just as it is important to start the meeting on time, it also is important to end the meeting the same way – on time. Closing comments might have the group leader or another group member

provide a topic summary of the meeting, and asking others if they have anything to add. Other topics are a reminder of the next meeting, date and time, and, if necessary, requesting volunteers for some aspect of that meeting (e.g., refreshments, identifying an interesting topic). The meeting generally closes with an expression of thanks for those in attendance and a comment about looking forward to seeing them at the next meeting.

9   Meeting Type – Open

Within the context of this Guide, open group meetings are those intended to allow for personal discussion among group members, to provide those members emotional support. As noted earlier, the recommended size for such groups is between six and eight members to better ensure that everyone gets a chance to participate. In the meeting notification, the group leader can set forth the meeting particulars, and may want to include a focus area for that particular meeting. It is suggested that notifications regularly invite group members to present their own ideas and thoughts on discussion topics, and/or to pose a question for discussion at the meeting. An example of an open group leader notification message is offered below:

> Date (7 to 10 days in advance of the meeting):
>
> Hello everyone,
>
> This is your reminder that we have our meeting this coming Tuesday, March 20th, from 6-7:30 p.m. at (location). We have had a request from a new member for a list of books that have been helpful to you in your journey, especially in the first year. If you have any books in mind, please bring their title and author with you, and maybe we can make up a list for everyone.
>
> Or you could send me your comments or suggestions by email when you respond as to whether you will attend the meeting this month.
>
> I leave you with the following quote from author unknown: "Making a Difference" – "An old man walked up a shore littered with thousands of starfish, beached and dying after a storm. A young man was picking them up and flinging them back into the ocean. "Why do you bother?" the old man scoffed. "You're not saving enough to make a difference." The young man picked up another starfish and sent it spinning back to the water. "Made a difference to that one," he said. Contemplating with you on the difference that we can make. (group leader)

Or alternative last paragraph

> In the meantime, consider this comment: "Caring for a person with a chronic illness is a journey that teaches us both about ourselves and also how to love in a new way." What has your journey taught you about yourself and loving in a new way? I look forward to your thoughts. (group leader)

9.1   Go-around

To give structure to an open meeting, you might choose a "go-around" format. Here, group members can share and learn about one another as a person, rather than as a PSCer/caregiver. For example, the go-around can provide information on one another's interests, skills, and circumstances, and can help build rapport between old and new members. It can help members refocus and to be more fully present at the group meeting. The go-arounds can be used at the beginning of each meeting, or can be the format for the entire meeting. The main focus is to hear from every group member without getting into a discussion about what any one member raises. All members are encouraged to take part; however, a member should also be able to choose not to take part, without this receiving undue attention. If a group member wishes to follow-up on a comment by another group member, this can take place after everyone else has finished his or her go-around.

9.2   Framing Questions

After explaining what a go-around is, or when otherwise felt appropriate (e.g., in another type of group meeting), the group leader or group member can put forth a "framing question". This is more of an open-ended question that can be helpful to both group members and the group leaders. These questions are generally positive in nature and invite a small amount of self-disclosure from all members (including you), while promoting brief responses. Some examples:

- Tell us an interesting thing about yourself that others might not know.
- Tell us your most unusual experience in dealing with PSC.
- Share with us the one most positive experience you have had from dealing with PSC.
- What do you hope to learn from (contribute to) this group?
- What makes you happy these days?
- Share with us something that you came across recently that you find inspiring.
- What is the greatest benefit/lesson you have learned from your involvement with this group?
- What is the one thing that people ask or say in regards to your PSC that is most appreciated?

From a medical aspect, some framing questions might include:

- Which of your PSC symptoms has had the most significant impact on you? On your family?
- From a humorous aspect (or not) what is the one comment/question that you wish others would stop asking?
- How did you (will you) tell your family (friends; employer) of your diagnosis?
- How have you advocated for yourself on your PSC journey?
- What do you believe is the most important role/responsibility for an advocate?
- What information did you receive from your doctor/other medical practitioners about PSC?
- What resources (written and oral) have been most helpful to you?
- If you have been involved in a research study, what was that like?
- If a person has had a transplant, what was the evaluation process like; what lifestyle changes have you had to make?
- How has PSC affected your relationships with others?
- What is it like to be a caregiver for your loved one?
- What challenges have you had to face; what do you do to manage your symptoms?

- If you ever have been involved with palliative care or hospice, what were those experiences like?
- What alternative medicine techniques have you tried, and what is your assessment of these?

It is important to remember that framing questions should not cross over into medical advice. Group leaders should help ensure that this does not occur.

9.3 Frequently Asked Questions

The type of questions raised at a meeting is likely to be determined by the group composition. Newer members, e.g., those recently diagnosed, may want to share comments they received from medical practitioners, for example, where such comments made the PSCer feel like he is being seen as "crazy". Another member may want to share her experiences in a specific area to see if others have experienced the same thing. In each instance, it is important to support the person, to perhaps share a relevant experience of your own, and to provide the person a sense of "hope", a feeling they are not alone. It is never appropriate, however, to offer a medical "diagnosis". Such diagnosis (not the discussion of the experience) must be clearly countered when it occurs in the group. An appropriate way to do this is to say this is a matter the person should discuss with his medical practitioner. Examples of such questions may include:

- My doctor says it is not possible for me to be experiencing this symptom, _____. Have others experienced this?
- Does anyone else have both _____ and _____? How do you –_____?
- My (parents, spouse, or __) doesn't understand _____. How have any of you dealt with this type of situation?
- I am tired of my (spouse, parent, other) asking me what my pain level is today. How can I best handle this?
- My doctor (medical team) is not listening to me? What can I do?
- How do you deal with (fatigue, insomnia, pain, transplant, medication lists/taking, etc.)?
- What do you do when you have a commitment (work/social/other) and you don't feel well enough to go? How do you say this to spouse/significant others/friends? Do you tend to make yourself go? What happens if you do go? How do you cope with these type situations?
- Have you told others (e.g., family, friends, and co-workers) about your PSC? How did you start the conversation? How did people respond? How did you feel afterwards?
- Are there any PSC focused on-line (Facebook, twitter) support groups that you have found helpful? Are there other resources (on-line, others) that you have found helpful?
- Who do you see/where do you go to get support?
- What is there that gives you enjoyment or relaxation, even if small, on a daily basis?

As can be seen, there is no limit on the questions that may be asked, other than phrasing it in such a way that any response is going to be more than a "yes" or "no".

A word of caution – when using a go-around and/or framing question it is important to carefully watch the time so that everyone gets a chance to talk. From the other perspective, many of the above topics might lend themselves to a full group discussion at an open meeting.

10 Meeting Type - Speaker

Some topics are instructive in nature and best handled by panel discussions or presentations. Ideally, the topic is one of group interest or otherwise considered important for the group. At the end of this section there is a listing of possible topics/speakers/panels relating to PSC.

In preparing for a speaker presentation, it is good to confirm the spelling of the speaker's name and contact information, as well as her credentials, and to see what if any equipment is needed. Also, confirm with the speaker the meeting location and time, and other particulars, and share some general information about the group, and areas of special interest. Whenever possible, the speaker should be requested to provide an advance, general outline of her presentation. [This helps ensure the desire topic is being covered while also avoiding "surprises" such as a speaker trying to sell specific services or products.] At the close of the presentation, it may be appropriate to thank the speaker with either a note or small gift. It also is recommended that a brief summary of the meeting be done, identifying topic, strengths of the presenter and presentation and any concerns. This should be maintained for future reference, including identifying additional subject matter that would be worth including if the topic was to be presented again at some future date.

A Listing of Possible Topics/Speakers/Panels relating to PSC

- An introduction to PSC.
- PSC-relevant medical practitioners speaking on the nature of their work with PSCers. Examples might include presentations by a hepatologist and/or a gastroenterologist.
- Other related medical practitioners (including those offering alternative medicine options). Examples might include nutritionists; physical therapists; hospital social workers, and others.
- On the mental health aspect of living with a chronic illness.
- On the transplant process from A to Z.
- On living with an invisible illness.
- On new research.
- On how to find a doctor within a given area.

The topics do not need to be limited to medical speakers. For example, among the possible topics/speakers/panels there could be:

- A practitioner presentation on the disability application process, both Federal and if one exists, on the state application process.
- A legal presentation on wills and estates.
- A financial planner to discuss investments, or another expert to discuss a specific topic in that person's specialty area. The meeting should be informal and allow sufficient time for questions and discussion.
- An interactive session on an area of interest to the group.

A third area for presentations could include looking at what is available on the PSC Partners website.

As can be seen from the above, there are a variety of topics, with these determined by the interests of the group members.

11 Meeting Type – Topic Oriented

It is important that group meetings reflect group member interest. This can cover a variety of options, ranging from a discussion of what has been occurring in the lives of group members to a more structured, topic-oriented program.

Examples of possible topic oriented programs.

- An overview of PSC and/or of recent events and occurrences regarding PSC.
- PSC Partners Patient Registry (see http://pscpartners.org/patient-registry/).
- Community outreach/resources.
- Fundraising.
- Organ donation.
- A discussion of available resources within the local (including regional) area.
- Navigating the PSC Partners website, and social media groups to keep aware of occurrences.
- Specific focus areas – nutrition, physical therapy.
- Discussion of a personal experience – e.g., family reaction to PSC; how my "invisible illness" affects my life, how I am perceived at work, etc.
- Avoiding caregiver "burnout".
- Increasing awareness of/sensitivity to individual and family needs.

For some of the above topics, outside presenters (medical practitioners, social workers, and community organization representatives) are needed/advisable.

Unforeseen events can occur at the last minute (e.g., speaker cancellation), impacting on a planned support group meeting. To recognize this possibility, it is strongly suggested that the group leader(s) maintain an alternate list of topics to use when needed. Possible examples: showing and discussing the "Faces of PSC" video; a discussion of an upcoming event/area of interest (e.g., awareness week; expanding the PSC network of community resources); or a group member sharing a recent experience and getting feedback from other group members on this experience.

As mentioned earlier in this document, the use of constructive humor may also be appropriate. One example: PSC stands for (must be other than primary sclerosing cholangitis). Some descriptive terms used in the past – Pretty Sexy Chicks; Please Send Cash. Another example – "I so hate it when….." thus allowing group members to share experiences in this area. Through the use of humor, the group may be better able to help lessen group sadness, while strengthening group bonding and providing an opportunity for an effective discussion among group members.

As a closing comment, it is suggested that there be an annual meeting review with group members to ensure that the schedule, format, and programs are supported by the group.

12 Additional Resources

Dystonia Medical Research Foundation – Support Group Manual, Dystonia Medical Research Foundation, Chicago, Illinois.

PSC Partners Seeking a Cure – website – www.pscpartners.org.

Pulmonary Fibrosis Foundation – Support Group Leader Guide - http://www.pulmonaryfibrosis.org/docs/default-source/support-group-leader/pff_sgl_guide_03-23-16.pdf?sfvrsn=0