

Guidelines

For

Support Groups

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INTRODUCTION

For most people, a diagnosis of cancer is an overwhelming experience. Fear of dying, worry about medical treatments, and concern over role changes at home or at work can make people feel isolated and alone at a time when they need other people the most.

Finding someone to talk to and share experiences with can ease the sense of isolation and reduce the stress. A support group for cancer patients gives people an opportunity to reach others in similar situations that are able to understand their feelings and concerns in a way people without cancer cannot.

Realizing that others have reactions and fears similar to theirs reassures patients that their own reactions are normal. Discussing problems and exchanging information and ideas with people who have first hand knowledge of what they are going through also helps group members learn how to cope with their own concerns. Whether the group is for people dealing with newly diagnosed disease, treatment options, or problems after treatment ends, group members can draw strength from each other when they share a common bond.

Participating in a group also gives people a sense of belonging and a place where feelings are accepted and understood. The group offers members a safe place to opening talk about fears and emotions they may feel uncomfortable discussing with people outside the group.

In addition to providing an emotionally supportive environment for members, the exposure to several points of view and shared experiences helps people find a way of

managing their own fears as well as dealing with those of friends and family. Learning coping skills and regaining a sense of control gives people a sense of wellbeing and hope.

Being a member of a support group also allows members a chance to act in the role of helpers. Group members can explain how they handled a problem and the suggestion may make things easier for the person currently going through it. This giving back makes people feel good about the group and themselves.

Because the psychosocial needs that arise from living through the cancer experience are not uniformly met in the health care system, hospitals, clinics and other health care facilities, recognizing the benefit of group support for cancer patients and their families and the increasingly active role patients are taking in their own care, create cancer support groups in their facilities as one way to help meet that need.

DEFINITION OF GROUPS

Most cancer support groups include patients and/or their families who meet under the leadership of a health care or mental health professional. These groups are not a substitute for treatment, but as a positive means of helping people use human relationships and connectedness to work on problems common to people with cancer. Cancer support groups help alleviate the psychological distress and social isolation experienced by many cancer patients and their families by providing a formal means for people in similar circumstances to share their ideas, feelings and coping strategies.

Because of the complexity of many of the psychosocial issues involved in group support, and to insure that participants receive a high standard of service and continuity of programming, some organizations prefer the professionally led support group model.

A support group is not a therapy group. While a therapy group focuses on change in interpersonal style, a support group focuses on mutual aid and support. A support group does not attempt to provide psychotherapy, medical care or treatment. The professional leader of a cancer support group acts as more of a facilitator than a leader. The group members help set the group's agenda, norms, content and structure.

Self-help groups include groups of patients and/or family members who meet under the leadership of a non-mental health professional. In these groups, leadership responsibility is shared by members of the group. A self-help group may, depending on its structure, vary in continuity and consistency. There are many kinds of self-help groups

and many different models for this type of group support. Most self-help groups begin spontaneously. Some are highly organized and have a national structure while others are only local. Some have leadership vested in certain members, other are professionally coordinated.

LIABILITY

It is important that volunteer social workers, nurses, therapists, physicians, etc. who are leading support groups or performing other professional services be advised that they are responsible for their own malpractice insurance coverage. Individual malpractice insurance generally provides coverage for monetary damages arising from negligent professional behavior such as giving inappropriate advice or failure to properly notify a physician or family member regarding a participant's being a possible risk for suicide.

Since self-help groups do not involve professionals acting in a professional capacity, malpractice issues are not a concern.

FEES

Most cancer support groups do not charge a fee for members to participate.

CONSIDERATIONS WHEN STARTING A SUPPORT GROUP

Resources may determine whether a volunteer or a staff member performs certain responsibilities. As with any volunteer/staff partnership, the important thing is to be clear on who will do what, by when, and to define next steps in the process.

Begin by forming a planning group. It may be helpful to recruit a health care professional who has a strong interest in group support programs. That person may be able to recruit other volunteers to serve on the planning committee. The planning committee should consider a variety of issues such as development of a needs assessment, staff and/or volunteer responsibilities, materials needed, recruitment, record keeping, evaluation, budget and the relationship the support group will have with other patient and family service programs.

If the group is going to have a professional facilitator, obtain resumes to determine the person's education and/or training in working with groups as well as practical experience.

Lay persons and professionals who have been patients or are family members of patients should be carefully screened before facilitation training to determine if they have resolved their own issues about cancer and achieved some distance and objectivity about them. Be aware of people expressing distrust of the health care system or state their personal opinions about the way to cope or treat cancer.

Group leaders/facilitators need to have a general knowledge about cancer and the psychosocial issues faced by cancer

patients and their families. They also need to have knowledge about group dynamics and individual behavior and feel comfortable with cancer patients in any stage of illness.

Whether the group is volunteer-led or professionally led, an effective leader or facilitator

- Has received training or demonstrated an ability to facilitate a group
- Has a working knowledge of group composition and group dynamics
- Acts as a role model for participants and is able to maintain objectivity
- Clearly understands the distinction between group psychotherapy and group support
- Is a people oriented person
- Demonstrates sensitivity to his/her own feelings about cancer, cancer treatments, and medical-social systems and understands how they may affect the group.

MEMBERSHIP RECRUITMENT

There are several ways to recruit members for a newly formed support group.

Flyers in clinics and hospitals, posters on bulletins boards, posting on websites are a good way to recruit members.

News releases about the group to the local media, as well as state, county and local medical, social work and nursing associations, health care facilities, nursing and social service departments, public health departments, home care agencies, and organizations dealing with psychological and social aspects of family can also be effective. It may be helpful to obtain public endorsements from clergy or community leaders.

Within the hospital, referrals usually come by word of mouth from staff and patients. Outside the hospital, referrals come from pamphlets, brochures or news releases.

It is important to establish and maintain contact with physicians and other health care professionals who can refer people with cancer to the group.

TYPES OF GROUPS

There are many ways of grouping individuals in support groups.

Heterogeneous groups include people with different diagnosis and/or family members or anyone else affected by a cancer diagnosis. The group may include people with all types of cancer, or a combination of people with all types of cancer.

Advantages: Since heterogeneous groups are open to anyone, they draw from a large source of possible members. This diversity lets participants see others in different stages of disease and learn how others have coped with various aspects of their illness.

Disadvantages: It is hard to build cohesion, support and mutual aid in an extremely diverse group where members share little with each other except for a cancer diagnosis.

Homogenous groups are limited to people who share something specific such as the same diagnosis, or the same stage of illness, the same age or ethnicity, the same treatment or healthy people at risk of cancer.

Advantages: The more people share in common, the faster they form a bond with each other and feel part of the group. Since all members share the same interest, facilitators can give more information about a specific cancer and treatment process. This type of group also increases member's sense of safety when discussing delicate issues.

Disadvantage: Providing homogenous groups for all diagnoses and relationships can be prohibitive since staff, facilitators, time and resources may be limited.

Types of homogenous groups:

- Specific cancer sites - for example, patients, friends and family of women with breast cancer
- Stage of illness – for example, newly diagnosed, currently in treatment, with a recurrence or people in remission
- Age specific – for example, young women, children of breast cancer patients
- Cultural/Ethnic specific – for example, African Americans, Native Americans, Hispanics
- At risk populations – for example, daughters of women with breast cancer
- Bereavement for those who lost someone with cancer
- Gender specific – for example, for women only. Men tend to prefer a very structured program with a clear agenda and time frame.
- Treatment modality specific – for example, people in clinical trials or radiation-only treatment

Open membership or open-ended groups are groups that are open to everyone with cancer and may include family and friends. The group may be ongoing with no established ending point or it may be time-limited. Although members may change from meeting to meeting, there is usually a core group who attends with some regularity and develops close personal ties.

Advantages: The advantages are similar to those for heterogeneous groups. Since they are open to anyone, they offer a large source of possible members. Open groups allow the inclusion of new members at any point in time, which can make the group seem more available and helpful to people who feel an immediate need.

Disadvantages: As members' needs change over time, there may be a tendency for them to become more social and less willing to integrate new members who may be experiencing the intense emotions of earlier stages. In addition, it may be hard to locate leaders willing to make an ongoing commitment. Maintaining open groups can be difficult and takes active and continued marketing efforts.

Closed membership or time-limited groups are groups that are limited to a specific group of people who meet for a specific time period. The members attend for a set number of meetings, usually with a specific focus or aim. Meetings tend to run between 6 to 12 weeks. New members are usually not allowed to join after the second session. Once the sessions are completed, the members stop attending as a group.

Advantages: Many people find comfort in knowing there is a clear end to the group cycle so they have control over the commitment they make. Since group membership is stable, people get to know and trust each other faster than in an open-ended group. It is usually easier to find a facilitator for a time-limited group.

Disadvantages: Sometimes there is no place to refer someone who does not want to wait until the next group is scheduled. In less densely populated areas, it may be hard to guarantee a sufficiently large group of committed participants for this kind of group.

Combined open-ended and closed membership groups

There are some groups that are open-ended but limited to people with a specific diagnosis such as women with breast cancer.

Advantages: Since membership is open to anyone with a particular diagnosis at any time, there is a large source of potential members. Having the same cancer site makes it easier for members to identify with each other's experiences, medical treatment, and emotional reaction. Although members may change from meeting to meeting, a dedicated core is usually formed.

Disadvantages: In a group limited to people with a specific diagnosis, there can sometimes be too much focus on site specific issues. This may cause over-identification and cause anxiety for some members. In addition, it may be hard to locate leaders willing to make a commitment to an ongoing group.

FORMAT AND GROUP SIZE

Structured groups have a set agenda. The facilitator or a guest speaker presents a specific topic at the beginning of each meeting. After the presentation, there is usually a question and answer period followed by group discussion. Each session's topic is set up by the facilitator, preferably with input from the group members. Structured groups tend to be educational in nature and work well when specific information needs to be passed on – for example, what to expect from radiation therapy.

Unstructured groups have no set agenda. The group discusses whatever issues come up at the meeting. Some people prefer this type of group because it encourages spontaneous discussion and exploration of whatever issues may arise. Less structured groups are more effective with a trained facilitator who is skilled in understanding and managing group dynamics.

Group size – Many experts believe the best size for a support group is a minimum of 5 to a maximum of 12 people, with 6 to 8 being the most effective size. This allows the group to be large enough to have good interaction and yet small enough to work on individual problems and allow everyone a chance to speak. Attrition is to be expected. Not everyone will attend every meeting and some people will drop out after the first session. Setting membership of a closed group at 10-15 usually results in a workable attendance. On the other hand, some groups can be quite large having as many as 30 or more participants. These groups should be led by a skilled facilitator in order for everyone's needs to be met.

FREQUENCY, LENGTH AND LOCATION OF MEETINGS

The frequency of meeting will depend on the needs of the participants and how much time the facilitator can devote to the group. **Weekly meetings** reinforce cohesion and continuity of the group. Meeting only once a month may make members feel disconnected creating a need to get reacquainted at each meeting and detracting from the continuity of the group. Meeting **twice a month** is a compromise between the two, which helps the group stay on track and allows for easier integration of new members.

Whether the group is open or closed, **a good length for a meeting is about 1 ½ hours**. This allows enough time for people to settle in and exchange ideas, feelings and thoughts with each other.

The **location** of the meeting should be in an atmosphere which is conducive to communication. Hospital-based meeting rooms can be uncomfortable for participants because of the constant reminder of their disease or treatment. However, many hospitals have small conference rooms that work very well for these meetings.

When choosing a location, consider the following:

- The facility should be easy to find
- It should be near a major highway or public transportation and have parking nearby
- It is best if parking is free
- The room must be large enough to accommodate the group but small and private enough to feel comfortable
- If possible have living room style furniture with chairs that can be grouped for easy conversation

- Hot water for coffee and tea is also appreciated and adds to the informal, conversational atmosphere
- Free babysitting may make attendance possible for people who would otherwise be unable to attend
- The meetings should take place in the same room for every session so participants know it is their room. A familiar space helps create cohesiveness.
- Avoid meeting where noise and distraction from other activities might disrupt the support group
- Try to find a place that will not charge a fee
- Restrooms should be readily accessible
- If members of the group are disabled or elderly, flights of stairs may be unacceptable
- Make sure there is always a key available or other means of entry
- There should be good security
- The facility should be in a well-lit site in a well trafficked area

ESTABLISHING MEETING GUIDELINES

Facilitators must establish norms or guidelines for meetings no matter how the group is organized. Setting boundaries let members know what to expect from the group and helps them feel more comfortable with each other. Ground rules need to be established at the beginning of the group and must be discussed and agreed to by the group members. For many people, this may be their first experience with a support group, not knowing what to expect can make participants feel anxious and nervous.

Confidentiality: Confidentiality must be established immediately. Members must feel safe enough to talk honestly and openly within the group. Explain that whatever is discussed in meetings will not be communicated to non-members. An exception to this rule would be if there is any self-destructive, hostile or suicidal behavior by a group member. If such an instance does arise, the facilitator has the responsibility to talk privately to the person involved and to make appropriate referrals and notifications.

Interruptions: Facilitators should request that members not be interrupted. This promotes mutual respect and helps members feel that what they have to say is important. It also encourages respect for other people's feelings by allowing all members the opportunity to express their thoughts and concerns.

However, it is the responsibility of the facilitator not to let one person monopolize the meeting to the detriment of the other members. It is also the responsibility of the facilitator to check to make sure that everyone who wishes to has had

an opportunity to speak and to invite quiet members to participate and share their feelings. Ensure members that they do not have to participate until they feel ready.

Meeting should begin and end on time. Setting boundaries helps members feel secure. Knowing they can count on a specific timeframe also allows them to make arrangements at work, or with family members.

PARTICIPANTS' ROLES

There may be several people involved with forming and maintaining a group.

Professional facilitator: The role of the facilitator is to promote cohesion, develop a safe environment, help support evolve, give information and foster stress reduction.

Professional consultant or advisor: When groups are not led by a professional facilitator, it is often useful to have access to a professional consultant or advisor. This person can help identify emerging problems, establish a plan for dealing with difficult or complicated issues, and advise on ways to promote a positive helping atmosphere. Even when there is a professional facilitator leading the group, the professional advisor can serve as a consulting peer or sounding board for any issues and questions the facilitator may have concerning the group.

Non-professional facilitator: Volunteers can serve as non-professional facilitators and provide structure and help maintain group focus. These are people who, with training, understand the group's purpose and can help guide the group needs.

Co-facilitator: Sometimes it is helpful to have two facilitators for a group. They can share leadership roles and tasks and also share expertise. Having co-facilitators is very helpful and maintains continuity of the group when one facilitator cannot attend the meeting. Co-facilitators can share observations about the group's needs and behaviors with each other. Co-leadership is also a good technique for training new group leaders and is a practical means of receiving feedback about one's effectiveness as a leader.

Group members: As in any group, members of support groups often help each other as a natural function of their participation. The most successful support groups are those in which virtually all the help obtained by members comes from the members and not from the leaders.

IDENTIFYING AND HANDLING PROBLEM BEHAVIORS

At some point every group leader will encounter people with problem behaviors.

The Monopolizer

Needs to tell his or her story in every discussion and wants to receive all the groups' attention.

- **Intervention:** The facilitator should try to acknowledge and subtly redirect the monopolizer's energy. For the benefit of the group it may eventually become necessary to directly confront the member exhibiting this type of behavior. Some monopolizers may actually be unacknowledged informal leaders. It is important not to compete with these members but try to bring them into the agenda and maximize their potential. Sometimes members of the group will themselves handle the situation.

The Complainer

The complainer complains all the time but refuses any helpful suggestions to make the situation better.

- **Intervention:** The facilitator should help the group confront the complainer and build on the positive. Focus on things that can be done. Use yourself as an example to redirect the complainer into taking constructive action and ask the complainer to actively engage in problem-solving.

The Hostile member

Unlike people who use anger to mobilize constructive action, the hostile member's anger is directed inappropriately at other members of the group. This kind of person is probably hostile outside the group as well.

- **Intervention:** The facilitator must take an active role to protect the group. Clarify group rules and norms. If the person cannot or will not conform to the group rules, privately ask that person to leave.

The Withdrawn member

This is the member who rarely or never talks or participates in the group

- **Intervention:** The facilitator should try and get the group to bring the withdrawn member in to the discussions. They should also watch for body language from the withdrawn member that might indicate it is a good time to invite them to comment. Support participation but do not demand it.

Special Need members

These are member who may have a hearing problem or language difficulties.

- **Intervention:** A facilitator may try to meet the needs of this person but must always consider the needs of the group as a whole and may have to make tough decisions regarding their continued participation.

Mental Health Problems: There is always the possibility that someone who is psychotic, deeply depressed or suicidal will make their way to a cancer support group. Usually these people do not function well within the group dynamic.

- **Intervention:** The facilitator should refer these members to a mental health provider or other available resources. If they gain control over their mental health condition, group participation may be appropriate.

THEMES OF DISCUSSION

Regardless of the type or structure of the group, there are certain themes that are likely to come up at meetings. Knowing these concerns in advance gives the facilitator a chance to think about and prepare for such issues when they arise.

Some of the most common themes are:

- The emotional impact of the illness
- The meaning of the illness
- Family difficulty
- Problems of intimacy
- A sense of isolation and/or stigma
- Role changes
- Cancer specific concerns
- Navigating the health care system
- Employment concerns
- Financial concerns
- Recurrence

PHASES OF SUPPORT GROUPS

The beginning phase: In the beginning phase, establishing trust is the most important task to be accomplished. Group members must learn to trust the facilitator and each other enough so they feel safe to openly discuss their fears and concerns. During the beginning phase members learn that others have had experiences similar to theirs. They seek information from each other and respond to practical information and alternatives in dealing with their problems.

The middle phase: Most of the work of the group occurs in the middle phase. Some groups work well when specific topics are suggested while others work well when members spontaneously determine the content. If a member brings up an issue which elicits strong group interest, the facilitator should encourage all participants to share their experiences and give each member a chance to contribute to the discussion. Members become open to self-examination and gain a greater sense of self-awareness and self-acceptance as they begin to recognize their own psychological and emotional needs. They share their experiences with each other, giving help as well as receiving it.

The end phase: The ending of a group represents a time of transition - either a leaving transition for those exiting the group, a reorganization of those staying in the group or the same transition if all members of the group are leaving. If a member leaves, the remaining members might feel happy or sad depending on the circumstances of the member's departure. If the entire group ends, feelings of happiness, sadness, anxiety, or relief may be expressed as part of the members' feelings of loss of the group. The facilitator should help identify the meaning and impact of the ending for all

participants so they can understand their own personal reaction in a larger context.

Time-limited groups have planned endings. Members know this in advance and expect the group will end on a specific date. Some members may find that after the group ends, they would like to continue reaching out to other people who are coping with similar cancer related issues. Members may arrange to continue to have information contact with each other or they may find another group to attend that will meet their needs. Some facilities provide another group for these members to transition into when the group ends.

ROLE OF THE FACILITATOR

In a support group all members are considered equal, with each person having an important contribution to make. The group as a whole however, needs someone to make sure meetings run smoothly and to help the group accomplish its purpose.

Self-help groups:

The leader's responsibility is to facilitate or guide members, sensing the group's current direction and assisting movement toward those goals. A good leader or facilitator is tuned in to the tone of the group and helps members work on their concerns. The leader or facilitator is not a controlling, directing figure. The leader is attentive to the needs of all members and responsive to the group's primary mission of creating a supportive environment.

The facilitator's role in a self led group is to:

- Keep members on topic
- Don't allow any member to monopolize the conversation
- Invite quiet members to participate
- Accept feelings as okay
- Suggest ways to solve a problem
- Summarize what members have said
- Encourage but don't pressure people to return
- Leave the door open for returning members

The strength of a group can be great when it realizes that no single person needs to possess all these skills.

Professionally led groups:

Members of a professionally led group rely on a health care or mental health professional to guide meetings but as in all groups, members gain strength, information and hope from each other.

The leader's responsibility is to

- Ask open-ended questions to encourage everyone present to participate in the discussion
- Guide conversation on topics determined by the group and not force a structured or lecture format
- Steer the group to possible alternatives to problems rather than allowing participants to focus exclusively on negative feelings
- Foster a caring atmosphere in which all feelings are accepted without judgment and encourage all participants to be honest and respectful of each other
- Follow up with members who miss a meeting
- Encourage but not pressure members to return to the group
- Always allow members to return to the group after an absence
- Summarize the discussion

TRAINING

Regardless of the amount of past training or experience, all group leaders need to consider the need for ongoing education by attendance at appropriate seminars, regular meetings with other facilitators or consultations with professional advisors to help deal with difficult situations and challenging group members. If a group is co-led, the leaders should meet on a regular basis for debriefing and to keep a clear and agreed upon perspective for the group.

FACILITATOR SKILLS

Developing good leadership skills is a long process which takes a lot of thought and commitment. Groups vary tremendously in their needs and facilitation must be tailored to the needs of each particular group.

Mistakes will happen but it is important not to become discouraged or intimidated. One can always learn when mistakes are made.

Provide Structure

It is the facilitators' responsibility to provide a structure within which the group process will occur. It is important to establish consistent meeting times, physical space that is comfortable and inviting and refreshments which symbolize a nurturing atmosphere. While the facilitator may allow a small amount of time at the beginning of the meeting for members to engage in social conversations, it is important to be respectful of time and refocus the group so newcomers do not feel apart from the group. There may be times when it is appropriate to hold a purely social event, such as a holiday, in order to balance the seriousness of the group process. Beginning and ending on time gives members a safe boundary and helps them feel

secure. Acknowledging that their time is important and valuable also builds self-esteem.

Provide information

The facilitator should be well-informed about cancer and about the psychosocial issues which will arise. While it is not appropriate to dominate a meeting with information or advice, it will be necessary to correct misconceptions about the disease or about treatment which invariably come up. There will be issues in which there are no sure answers and the facilitator needs to be comfortable helping members explore feelings and ideas. Group members need the security of knowing that the facilitator is a resource and promotes the group process.

Promote a sense of cohesion

It is important to help people join together and experience how alike they are in their emotions and issues. Sometimes members challenge this sense of group togetherness by being critical or monopolizing. Facilitators should try to offer balance to these negative comments and refocus the group.

Develop a safe place

Many members have never participated in a group before and are nervous about what to expect. Acknowledging their anxiety and applauding the courage it took for them to come to group helps put them at ease. One approach would be to ask new members to introduce themselves to the group and tell a little bit about their own experiences if they feel comfortable enough to do it. This demonstrates that each person is important and will be listened to. It also shows members what experiences and feelings they share in common with each other and helps to establish cohesiveness in the group. Facilitators should never push for self-disclosure

or engage in interpretation of a member's behavior as might happen in a therapy group. People come to support group for support not for personal change. Keep comments to the group not the individual.

Help members support each other

It is important for group members to have a sense of what to expect from themselves and from other members. Some people react to the stress of cancer by becoming overwhelmed and helpless. It is important to encourage behavior that promotes members to take charge of their issues and look for solutions. Setting ground rules at the beginning of each meeting such as issues of confidentiality and encouraging everyone to participate, helps both old and new members know what to expect and what their role is in the group process.

A facilitator who can truly listen and relate to the emotions that are expressed creates a supportive environment in which people can gain strength from each other. This demonstration of empathy teaches the other members how to respond and builds their skills as helpers. Humor can be helpful in diffusing some of the tension that may be generated when the group is dealing with strong emotions.

The facilitator should avoid giving advice. Everyone experiences cancer in a unique way. No two people react to chemotherapy exactly the same way or have exactly the same disease process. People have their own coping methods, their own techniques for gaining control, and their own unique ways of relating to others about their disease. Remind participants to limit their input to their own personal experiences and to avoid telling another member what they should or should not do.

While members share many experiences in common, they may find some coping mechanisms work better for them than others. Therefore a facilitator should maintain a balanced discussion of coping mechanisms without dwelling on any one to the exclusion of others. Humor, mediation, imagery, counseling, support groups, relaxation techniques, reading, recreation are all tools members can use, perhaps at different times.

Reinforce the positive

Sometimes in a group a member's behavior becomes counterproductive to effective problem-solving. For example, if a member is angry and wants to confront her physician, a discussion about how to get her needs met that would result in a more positive outcome for her and her relationship with her physician would be helpful not only for her, but for all the group members. It is easy for a group to develop a negative, complaining tone if criticism of the health care system becomes the norm. It is not productive to deny the difficulties or the distressing feelings that accompany these kinds of problems, but by discussing the use of a more positive approach the facilitator helps the group develop more productive approaches to problems. This also allows members to see a better way to engage members of the group and assists the facilitator in handling negative behaviors. Members' self-esteem is enhanced as they feel more in control of problematic situations.

Core group

A core group of members usually forms within an open-ended group. These dedicated core members form a unified, cohesive, trusting center and are valuable for the longevity of the group. This group attends most meetings. Members may wish to exchange phone numbers and get in touch with each other between group meetings for social

interactions. It is important however, not to let the core group become a clique which may overtly or covertly exclude new members. One way to avoid this is by giving the core group the responsibility of greeting and integrating new members.

Members who drop out

In any ongoing group it is normal for people to drop out. This is not necessarily a sign the facilitator is doing anything wrong. People drop out for a variety of reasons. The meeting times may no longer be convenient for them, or they finished treatment and have returned to work. Sometimes their needs have been met and they think they would no longer derive any benefit by continuing to attend. If someone drops out from a closed or time-limited group it is a good idea to contact them to find out the reason and share that with the remaining group members.

DO'S AND DON'T FOR GROUP LEADERS

DO

Participate

Provide information

Encourage everyone to talk

Communicate empathy

Clarify people's feelings

Let group members
explore strong feelings

Protect members
from hostility

Support and balance
opposing views

Prepare an agenda for discussion

Use structure to reduce
members' anxiety

Acknowledge group tension

Use humor to reduce distress
or bring people together

Encourage members to explore
important questions

DON'T

take over

lecture

pressure them to do so

focus on your own story

prevent members from
doing this themselves

rescue them from
their feelings

block appropriate expressions
of anger

take sides

insist on it

use structure to reduce
facilitators' anxiety

avoid tough situations

use humor to distract
or avoid

assume you must have
the answers

SPECIALIZED SUPPORT GROUPS

There is a natural tendency for people to come together when they share common needs, concerns, and problems. The following are types of specialized support groups.

Groups for children: Groups for children can be hospital, community or school-based. They are somewhat unique in their need for professionally-trained facilitators since children's development needs greatly influence their response to illness. Structure is also very important for children's groups. Unlike adults, children cannot be expected to verbalize their feelings, therefore all activities should include a structured activity such as drawing, and games etc., which can help children express their feelings.

The pre-school child as the patient

The school-age child as the patient

Adolescents as patients

Children whose parents have cancer

Children whose siblings have cancer

Bereavement groups for children

Groups for parents of patients: Short of a child's death, there is nothing more traumatic for parents than to have a child diagnosed with cancer. Self-help groups for parents often spring up spontaneously and may be coordinated by parents.

Groups for young adults with cancer: A diagnosis in a young adult can disrupt significant life decisions and plans such as school, career, marriage and becoming a parent.

Bereavement groups for adults: A bereavement group can help people take the time they need to get through and normalize the various feelings of the grieving process.

Cultural specific group: Cultural groups often have issues that are unique to that population.

EVALUATION

Regardless of the type of group, it is important to evaluate the group to determine whether or not it is meeting the needs of its members. Questions to consider could include, did participants receive the support, information and guidance they expected from the group? How did joining the group impact their life or their relationship with their friends and family? Asking a participant to fill out a questionnaire is a good way of doing this.

FACILITATOR SUMMARY

It is also helpful for the facilitator to document group activity. At the end of each meeting, they should record the themes covered in the session and any other relevant observations. This information helps the facilitator identify any recurrent problems so any structural changes can be made to improve the group process.

EVALUATION

Date _____

1. How did you learn about the group?

A friend _____ Referred by a professional _____

Flyer _____ Newspaper _____ Other _____

2. Is this your first meeting? Yes _____ No _____

3. Will you attend future meetings? Yes _____ No _____

4. Please assess the following aspects of the meeting...

	Very Satisfied	Somewhat Satisfied	Not Satisfied
Structure of the meeting			
Format of the meeting			
Length of the meeting			
Opportunity to talk			
Time of the meeting			
Location of the meeting			

5. How helpful was the group for you?

Not helpful _____ Somewhat helpful _____

Very helpful _____ Extremely helpful _____

6. Describe briefly what was most helpful to you:

7. What did you get or learn from the group that you wanted to get or learn?

8. What did you like most about the group?

9. What did you like least about the group?

10. Do you feel any different about yourself after the group?

Yes _____ No _____

If yes, what has changed?

11. Have you changed any behavior, ways or habits since participating in the group?

Yes _____ No _____

If yes, what has changed?

12. Please comment or provide suggestions for future groups and or suggestions for improvement.

Facilitator Group Summary

Date: _____ Facilitator Name _____

Group name _____

Meeting location _____

Frequency of meetings _____

Group format _____

Total number of Participants _____

Number of Patients _____

Number of Support persons _____

Discuss themes covered in this session and other relevant observations _____

Concerns

Considerations for next meeting

Date of next meeting

Resources

Internet resources for Breast Cancer Information:

www.komen.org

Susan G. Komen for the Cure®

Information and resources about breast cancer

www.nci.nih.gov

National Cancer Institute

National Institute of Health

Information and resources about all cancers

www.nccn.org

National Comprehensive Cancer Network

Information and resources about all cancers

www.cancertrials.nci.nih.gov

National Clinical Trials Database

www.aacr.org

American Association for Cancer Research

Cancer research for all cancers

www.cancernetwork.com

Cancer Information Network

Leads to interactive decision tree

www.cancer.org

American Cancer Society

General and specific information, statistics and services

www.cancercares.org

CancerCare

Professional support for people affected by cancer

www.asco.org

American Society of Clinical Oncology

Organization for Clinical Oncologists

www.cancer.net

Oncology approved information from the American Society of Clinical Oncology – appropriate for patients as well as professionals

www.aicr.org

American Institute for Cancer Research
Organization whose research is focused on diet, physical activity and cancer prevention

www.oncolink.upenn.edu

OncoLink provides comprehensive information on treatment and research advances

www.ons.org

Oncology Nursing Society
Organization for Oncology nursing and other healthcare professionals involved in oncology care

www.patientcenters.com

Breast Cancer Center
Information about Metastatic breast cancer

www.breastcancer.org

Breast Cancer.org
A medical oncologist answers questions on breast cancer

www.cancerlinks.org

CancerLinks
Offers links to information on all cancers

www.nlm.nih.gov/medlineplus/breastcancer.html

Medline Plus: Breast Cancer
Resources linked for the latest news

www.cansearch.org

National Coalition for Cancer Survivorship (NCCS)
Step by step instructions on researching the internet

www.cancercares.org
Cancer Care, Inc.
Assistance to patients and their families

www.lbbc.org
Living Beyond Breast Cancer
To empower women to live the best quality of life after cancer

www.nabco.org
National Breast Cancer Organization (NABCO)
Network of breast cancer organizations

www.lymphnet.org
National Lymphedema Network (NLN)
Education and information about Lymphedema

www.lbcresearch.org
Inflammatory breast Cancer (IBC) Research Foundation
Information about inflammatory breast cancer

www.interact.withus.com/interact/mbc
Breast cancer in Men
Information and resources about male breast cancer

www.wellness-community.org
The Wellness Community
Provides emotional support to cancer patients

www.plasticsurgery.org/surgery/brstec.htm
Plastic Surgery information Service
Breast Reconstruction following breast removal
Information from the American Society of Plastic and reconstructive Surgeons

www.preventcancer.org
Cancer Research Foundation of America
Funds research on cancer prevention