

Organizing and Facilitating a Support Group



FOCUSING ON SUPPORT



American Brain Tumor Association

A Word About ABTA

Founded in 1973, the American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumors. Since then, ABTA has been a consistent leader in brain tumor research and patient and family support.

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The Need for Support Groups

When someone has been diagnosed with a brain tumor, they, their family members and loved ones can feel isolated, alone, frightened, and unprepared to face the challenges associated with the disease. A support group, which brings together individuals with similar concerns and uncertainties to exchange ideas and provide mutual encouragement, may help.

Support group participants exchange practical information and insights about brain tumors, and related care and treatment. Participants can learn more about their illness, and how to communicate effectively with doctors, medical staff and insurance providers. In addition, a support group can help patients and family members to better cope with their diagnosis and treatment, and adapt to any resulting physical and/or mental changes and limitations.

There are several types of support groups. The appropriate support group (or the decision to join a support group) depends on the individual's particular needs.

Types of Groups

Open Ended Groups

Open ended support groups meet at set intervals, such as once or twice a month, for an indefinite period of time. People can join the group at any time and attend as few or as many meetings as they wish. Open ended groups can be more difficult to lead because new members are continually changing the group's dynamics. The challenge to the facilitator is to

integrate new members while not making the sessions overly repetitive for returning participants. In addition, potential new members determine if the particular group, or any group setting, is appropriate for them. However, as this is the most practical format for brain tumor support groups, most brain tumor support groups are open ended.

Closed Time Limited Groups

Closed time limited groups meet for a set number of sessions, commonly six to 12 times over the course of a few months. The facilitator usually interviews potential participants in advance to ensure that the individual and group are a good match. Each session has a specific goal. The closed time limited group offers members the opportunity to develop close relationships because there is more time for interaction and to explore important issues in depth. There are no distractions due to new members joining the group.

Mechanics

Assess The Need In Your Community

Contact the American Brain Tumor Association (ABTA) for a current list of support groups in your community. If there are established groups, check them out: Are they only for patients, or do they allow family and friend participation? Do they limit membership in any way? Is there a need for a psycho-educational based format? After a thorough assessment, if you determine that an additional brain tumor support group is needed, there are several other factors to consider.

Who Will Lead The Group?

Groups can be lead by paid or volunteer professionals, by group members, or by a combination of both. Group leaders are also called “facilitators” because they make it easy and comfortable for everyone to participate in the discussion. In addition, facilitators intervene and help participants work through confrontations or disagreements. Groups run by patients and family members are often called “self-help” rather than “support” groups. Self-help group members share experiences and learn coping skills from each other.

Professionals, such as social workers, counselors or psychologists, often have training and experience in running groups and have knowledge of group theory. They might be better equipped to handle problems that arise, such as one individual monopolizing the group, or if someone has needs that can't be met by the group. In addition, professionals might be more qualified to screen new participants than group members.

Co-leadership should be considered as it provides several advantages. If one leader is unavailable, a co-leader could provide continuity. Co-leaders can provide each other with the support they might need, and the opportunity to share emotionally difficult information that can arise during a session. If the co-leaders are from different disciplines, a blending of skills is often a bonus. However, co-leadership might not be feasible for some groups. In those instances, the group leader will need to seek their own resources and support.

Location And Meeting Schedule

The facilitators must find a safe, convenient meeting location that can be used on a regular basis. Possibilities include hospitals, community centers, libraries, schools, or religious institutions. Determine how often you want to meet and a meeting time that will be most convenient for the people who will be attending. Other items of importance when scouting locations are barrier-free environments, and the convenience and affordability of parking. The location of rest room facilities and a coatroom are other considerations. If refreshments will be part of the meeting, make sure there is a serving and clean-up area. A check-in area, and space to accommodate handouts and/or other printed materials, should also be provided.

Format

Groups need to establish goals and a meeting format. Some groups have guest speakers, discussion groups, or a combination of these formats.

Publicity

- Begin to publicize your group by notifying ABTA, local cancer organizations such as the American Cancer Society, and social service agencies.
- Write an announcement or an article about your group and send it to your local newspaper.
- Send PSAs (public service announcements) to local TV and radio stations.

- Send an announcement to libraries, physicians' offices and appropriate hospital departments of nursing, social work, neurosurgery, neurology, and radiation oncology.
- Create an inexpensive flyer, and ask area hospitals to place it in their resource or information centers.
- Contact your local cable company to let them know about your group and your availability for interviews
- Arrange special guest speakers and let local newspapers know the dates of your presentations well in advance.

Remember that support groups are dynamic entities. When people outgrow their need for a support group, they stop attending meetings. Problems can arise if the size of the group decreases to the point that it becomes stagnant. Therefore, a constant inflow of new members is needed if the group is going to successfully continue. Attracting new members must be an ongoing effort. Frequent reminders directed to the medical community and the patient public is important.

Funding Opportunities for Your Group

If your group meets in a hospital, ask the Social Work Department or health care foundation within the hospital for funds to pay for refreshments or printing and mailing expenses.

- Contact members of your health care team and ask them for financial assistance.
- Solicit pharmaceutical companies, especially those that produce medications used by brain tumor patients.
- Write grants to charitable foundations.
- Solicit contributions from group members.
- Solicit sororities and fraternities that do charitable work.
- Solicit prizes, and then hold a raffle.
- Solicit companies for contributions. As an example, a pediatric support group has asked stores for t-shirts and toys for parties they host twice a year.

How ABTA Can Help

The American Brain Tumor Association (ABTA) offers a Support Group Mentorship Program. If you are interested in starting a new support group, an ABTA social worker can match you with a mentor who has experience facilitating a brain tumor support group and can address any questions or concerns that you may have about starting and maintaining a brain tumor support group. Your mentor will be available to help answer your questions as the group evolves.

In addition, ABTA can help you publicize the new support group by mailing your announcement flyer to patients, caregivers, family members, friends and health care professionals. Also, we can help you write the announcements or PSAs and send you free samples of our publications to have available at the first group meeting. Once your group is up and running, we can add your group's contact information to our current listing of support groups, which is made available to patients, family members, and health care professionals.

If other questions arise, ABTA is available to help. We can be reached at: 1-800-886-2282, or info@abta.org.

Resources for Support Group Leaders

These suggested readings can help group facilitators provide effective leadership and assist them in achieving the group's goals.

Aguilera, D. 1998. *Crisis Intervention: Theory and Methodology*. 8th ed. St. Louis, Mo: Mosby.

This book illustrates how crisis intervention can be used as an effective mechanism in coping with situational and maturational crises. It can be used by the leader to help a group member recognize the stresses and tensions they are experiencing. The leader and member can then proceed to develop an appropriate coping strategy for the cited problem.

American Cancer Society. 2001. *Cancer Support Groups: A Guide for Facilitators*. Atlanta, GA: American Cancer Society.

This publication provides general information on developing and maintaining a support group. It's concise, easy to read, and in an outline presentation that makes this a handy resource to have at every meeting. It provides the leader with specific goals for members to achieve and defines the role of the leader. Additionally, it discusses important elements that are essential to health group development. Guidance in developing questionnaires to effectively evaluate the benefit of the group on its members is provided. An extensive bibliography on group work is included.

Corey, Marianne Schneider, and Gerald Corey. 2006. *Groups: Process and Practice*. 7th ed. Belmont, CA: Thomson Brooks Publishing.

Written by a husband and wife team—one a private practitioner, and one an academic—this text outlines the basic issues and concepts of group process and presents guidelines for working with various types of groups. Coverage includes ethnical and legal issues, stages of group development, and the application of group process to specific groups, such as children, adolescents, adults and the elderly.

Healy, Bernadine. 2007. *Living Time: Faith and Facts to Transform Your Cancer Journey*. New York, NY: Bantam Publishers.

Imagine you were both a former head of the National Cancer Institute and the American Red Cross, and you were told you had a brain tumor. Would your journey differ from anyone else's? In this book, Bernadine Healy, MD, shares her personal experience in the world of brain tumors. She conveys her experience of hearing the words "brain tumor" (an oligodendroglioma), the challenges of treatment, and her road to survivorship. The story is eloquently written and very readable, helping the facilitator to better understand the journey of a brain tumors patient.

Larson, D. 1993. *The Helper's Journey*. Champaign, IL: Research Press.

This book seeks to develop the "helper" in all of us. It discusses the characteristics a group leader needs to acquire and develop,

particularly the need to be sensitive to the subject matter, as well as communication techniques utilized by members. It provides seasoned leaders with the tools they need to sustain sensitivity without risk of burnout. Techniques for dealing with the range of emotions that accompany life-threatening illnesses are discussed.

Laura, Mari M., Clark, Elizabeth J., Hermann, Joan F., and Stearns, Naomi M., 2001. *Social Work in Oncology: Supporting Survivors, Families and Caregivers*. Atlanta, GA: American Cancer Society.

This book is a valuable reference tool for the new social worker as well as for the experienced social worker new to the oncology field. Includes information on the emotional and social impact of cancer on children, the range of social work interventions applied in cancer care, professional issues in oncology social work, the identification and access of available resources, and the latest information about diagnosis and treatment. Also included is a special patient information section on understanding and using support services.

Shives, L. 2007. *Basic Concepts of Psychiatric-Mental Health Nursing*. Philadelphia, PA: Williams & Wilkins.

Chapter 10 of this book provides historical and background information on support groups. Leaders will find this information valuable because it clearly defines different types of groups. It also provides information on group development and defines the role of the leader with emphasis

on how to facilitate communication. For the leader who wants to expand his/her knowledge, Chapter 11 provides insight into family dynamics. This information can help a leader recognize if a family is unable to cope, and whether other types of support or counseling should be suggested.

Stark-Vance, Virginia, and Dubay, ML, 20 *Questions & Answers About Brain Tumors*. Sudbury, MA: Jones and Bartlett Publishers.

Patients, families and professionals all can learn from the answers and commentaries found in this book. Ms. Dubay provides clarity that only a patient would know how to address and Dr. Stark-Vance responds to the questions with candor and sound medical expertise.

Yalom, I. 2005. *The Theory and Practice of Group Psychotherapy*. 5th Ed. New York, NY: Basics Books.

Detailed information about therapeutic factors that are essential elements of the group process is provided in this book. It includes discussions about the stages of a group's development and elaborates about members' roles in the group. This helps leaders direct and channel inappropriate communication into constructive group work. This book contains an in depth discussion of groups and is an important resource for group leaders.

Caring for the Support Group Leader

- Set limits for yourself. You can only do so much.
- Recruit a co-facilitator. If you need to miss a meeting, a co-facilitator serves as your back up. Having someone to share the difficult times is beneficial and can also provide relief.
- Find someone outside the group with whom you can share your feelings. Distress or sorrow shared is lessened.
- Leading a group can be physically as well as emotionally exhausting. A good night's sleep and periods of relaxation during the day are important to both your mind and body.
- Meditation or relaxation exercises, even briefly, can help reduce stress. Various books, audio-tapes and videos are available to learn these techniques.
- Learn to say “no.” You aren't being selfish—you are avoiding an overload.
- If you need help, ask a member of the group. They would probably be honored to be asked, and will appreciate being needed.
- Laugh out loud and often. Humor helps heal.
- Relish the gratitude of the group for your efforts and realize you have benefited the group members significantly.
- Look to a higher power. Prayer is a wonderful means of seeking help.

Questions I Want to Ask

This publication is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician(s), utilizing your specific medical information. Inclusion in this publication is not a recommendation of any product, treatment, physician, or hospital.

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