



American  
Brain Tumor  
Association®

*Providing and pursuing answers®*

# Organizing and Facilitating a Support Group



## The Need for Support Groups

When someone has been diagnosed with a brain tumor, the patient and their loved ones can feel isolated, frightened and unprepared to face the challenges associated with the disease. A support group can alleviate these anxieties by providing an opportunity for participants to share mutual experience, ask questions, exchange ideas and provide comfort through talking with others with similar concerns and uncertainties.

Support group participants exchange practical information and insights about brain tumors, 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 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 needs.



### Types of Support 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 are open ended.

#### Closed-Time Limited Groups

1·2·3·4·5·6·7·8·9·10·11·12

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. There are no distractions due to new members joining the group.

#### Online Support Groups

Online support groups, discussion boards and blogs are another way to connect. Members of these support communities like the convenience and privacy offered online. The ABTA offers an online support community called "*Connections*". Learn more at [www.abta.org](http://www.abta.org).



## Mechanics

### Assess the Need in your Community

Connect with the American Brain Tumor Association (ABTA) at **800-886-ABTA (2282)**, **ABTAcares@abta.org** or **www.abta.org** for a current list of support groups in your community. If there are established groups, check them out and consider:

- 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 led 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 dynamics. 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

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, such as a nurse practitioner and social worker, 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.



The ABTA offers a support group facilitator training program.

Visit [www.abta.org/supportgrouptraining](http://www.abta.org/supportgrouptraining) to learn more.

### Location and Meeting Schedule

The facilitators must find a safe, private and 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 participants.

Other items of importance when scouting locations are accessibility for those in wheelchairs, and the convenience and affordability of parking. The location of restrooms 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. If you plan to use electronic presentations, such as Powerpoint, ensure location has the capabilities to use those tools.

It is important to discuss the location with the entire group periodically, as the needs of the group may change as new members are added or members' situations change.



### Format

Groups need to establish goals and a meeting format such as open ended or closed group. Some groups also have guest speakers, discussion groups or a combination of these formats.

### Publicity

- Begin to publicize your group by contacting local cancer organizations, local libraries and social services agencies to get your group added to their calendar listings
- Reach out to the ABTA to add your group to the support group listings webpage on [www.abta.org](http://www.abta.org)
- Send an announcement to physicians' offices and appropriate hospital departments of nursing, social work, neurology, neurosurgery and radiation oncology.
- Write an announcement or an article about your group and send it to your local newspaper.

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 flow 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 the hospital's health care foundation for funds to pay for refreshments or printing and mailing expenses to promote the support group.

- Contact members of your health care team and ask them for financial assistance resources. Brain Tumor/Neurology/Neurosurgery clinics may also be interested in sponsoring the group.
- Request funds from pharmaceutical companies, especially those that produce medications used by brain tumor patients.
- Write grants to charitable foundations.
- Ask for contributions from group members.
- Consider asking local companies for contributions. Local restaurants may be interested in donating refreshments. Other local stores may donate items for special events hosted by the group (i.e., holiday parties, family picnics etc.)



### Caring for the Support Group Leader

Facilitating a brain tumor support group is a challenging yet rewarding endeavor. The support group leader serves a very important role in organizing, maintaining and ensuring the support group is effective for all those involved. It requires a person who is able to adapt and manage various personalities, situations and topics. It is important for those leading the group to also care for themselves. These tips have helped other support group facilitators:

- 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 in the difficult times is beneficial and can provide relief.
- Find someone outside the group with whom you can share your feelings. Distress or sorrow shared is lessened. Respect group members' confidentiality by not sharing identifying information during these conversations.
- 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 for both your mind and body.
- Meditation or relaxation exercises, even briefly, can help reduce stress.
- Learn to say "no." You are not 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.
- Relish the gratitude of the group for your efforts and realize you have benefited the group members significantly.
- Look to a higher power. Prayer can be a wonderful means of seeking help.

## About ABTA

Founded in 1973, the American Brain Tumor Association was the first and is the only national patient advocacy organization committed to funding brain tumor research and providing support and education programs for people of all tumor types and all ages.

## American Brain Tumor Association Publications

- About Brain Tumors: A Primer for Patients and Caregivers
- Brain Tumors — A Handbook for the Newly Diagnosed
- Brain Tumor Dictionary
- Caregiver Handbook
- Returning to Work: Accessing Reasonable Accommodations

### Tumor Types:

- Ependymoma
- Glioblastoma and Malignant Astrocytoma
- Medulloblastoma
- Meningioma
- Metastatic Brain Tumors
- Oligodendroglioma and Oligoastrocytoma
- Pituitary Tumors

### Treatments:

- Chemotherapy
- Clinical Trials
- Conventional Radiation Therapy
- Proton Therapy
- Stereotactic Radiosurgery\*
- Steroids
- Surgery

*Most publications are available for download in Spanish. Exceptions are marked \**

**More brain tumor resources and information are available at [www.abta.org](http://www.abta.org).**

### How Can ABTA Help

- **Brain Tumor Support Group Facilitator Training Program** — gain the tools to successfully facilitate the unique needs of brain tumor patients and caregivers.

*Nurses and social workers completing the four course online training program — available at no charge — will be awarded 4 Continuing Education Units (CEU\*s) approved through the AANN and NASW.*

[www.abta.org/supportgrouptraining](http://www.abta.org/supportgrouptraining)

- In conjunction with the American Association of Neurological Nurses (AANN), the ABTA developed Clinical Practice Guidelines for the **Care of an Adult and Pediatric Brain Tumor Patient** for nurses providing care for a brain tumor patient.



- **ABTA Connections** is a 24/7 online support community that links patients, families and friends with each other for support and inspiration.



\* This continuing nursing education activity was approved by the American Association of Neuroscience Nurses, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

\* This program is Approved by the National Association of Social Workers for Social Work continuing education contact hours.



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**For more information contact:**

 **Call:** 800-886-ABTA (2282)

 **Email:** [info@abta.org](mailto:info@abta.org)

 **Visit:** [www.abta.org](http://www.abta.org)

 [Facebook.com/theABTA](https://www.facebook.com/theABTA)

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