

# **DEVELOPING A SUCCESSFUL BRAIN INJURY SUPPORT GROUP**

A service of The Brain Injury Association of Florida, Inc. (BIAF)



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It should be noted that in this guide the terms head injury, brain injury and traumatic brain injury are used interchangeably.

## ***Letter from President and CEO***

Dear Support Group Facilitator,

Thank you for your interest and commitment to volunteer your time to help support members of the community whose lives have been affected by traumatic brain injury (TBI). Please know that as you embark on this effort, you are not alone.

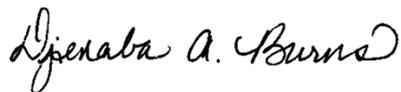
Since 1985, the Brain Injury Association of Florida, Inc. (BIAF), has remained your *only* statewide organization committed to individuals experiencing brain injury, their families and, caregivers. Our mission is to “improve the quality of life for all persons with brain injury and their families by creating a better future through brain injury awareness, research, prevention, education, support services and advocacy”. Community based support groups are a critical component to our mission in the areas of awareness, education and advocacy, and BIAF remains by your side to help guide your efforts and partner in a positive way.

The BIAF provides a toll free helpline (**800-992-3442**) where for the past 30 plus years we have listened carefully to the voices and the needs of hundreds of thousands of survivors of brain injury and their families- giving us the insight to help you guide and support members within your group and community. The BIAF has certified brain injury staff located throughout Florida to answer questions and provide education and resources to you and your members. As your State Association we keep our thumb on the pulse of what’s going on in the field of brain injury and the changing opportunities presented to the brain injury community- making us your trustworthy “safe place” to provide guidance and help should you need advice.

The BIAF hosts the Florida Department of Health’s Traumatic Brain Injury Resource and Support Center where hundreds of educational materials for survivors of brain injury, caregivers and professionals are housed at [www.byyourside.org](http://www.byyourside.org) and our trained professional staff are available to help translate information and find resources based on the families’ needs throughout their journey. We also provide opportunities for members to participate in our signature event, WalkAbout Brain Injury© during March-national brain injury awareness month, where members can help raise awareness and dollars to help the BIAF continue its mission.

As you consider developing and leading a support group in your area, please do not hesitate to reach out to the BIAF staff. Leading a group of persons with brain injury and their families can be both challenging and rewarding. Unfortunately, resources for individuals and their families are limited, so working together in the areas of community awareness, education and advocacy are the first steps in creating a successful future.

Sincerely,



Djenaba A. Burns, President & CEO

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## **HOW TO USE THIS GUIDE**

Each area discussed in the manual provides a number of specific suggestions you may find applicable to your group. Once you determine which areas you would most like to focus on, you can go directly to those sections. You and your group can then decide together whether the ideas and suggestions provided there will strengthen your primary purpose for being together.

Remember, especially when people and personalities are involved, there is never only one best way to do things. You may already be doing everything you can in a certain area and that may very well be what is best for your group at this particular time, in spite of what the guidebook says.

The publishers grant permission for photocopying all or parts of this material for use by support group leaders and individual members in developing and strengthening their efforts to assist people with brain injuries and their families.

## **WHY ATTEND A SUPPORT GROUP MEETING**

The purpose of a support group is to share and support one another for the mutual benefit of the total group.

Some essential elements of a support group are sharing one's own experiences and finding out more about life with a traumatic brain injury (TBI) by learning from others' achievements and strategies. Support groups are safe places where everyone supports each other and knows that what is shared in the group remains confidential. Support groups are a two-way street in that a member can feel supported just by having peers around them who have gone through similar situations. It is an environment where both positive and negative views can be expressed without being judged or labeled.

Support groups consistently create an environment for developing friendships, social skills and community involvement.

## WHAT MAKES A GOOD FACILITATOR

As a facilitator, connecting with group members is important. How you approach and react to different situations can help strengthen the group bond. There are several characteristics that help make a person a good facilitator. These include:

**Flexibility.** The plan may not always go exactly as intended. A speaker may have to cancel at the last minute or there may not be enough chairs available in the room. Whatever the situation, having a flexible attitude decreases stress.

**Honesty.** Sharing information honestly increases the amount of trust group members have in you. Speaking with honesty and passion promotes group participation.

**Ability to inspire.** It can be easy to dwell on difficulties after sustaining a TBI, but there are many positive outcomes and learning experiences that take place. Encouraging group members to remember the victories, even if they are small, can help make for a more successful group.

**Positive attitude.** Maintaining a positive attitude while leading the support group encourages the members to have optimism. This outlook is also a coping strategy that can help when dealing with difficult situations.

**Energy.** Provide energy by remaining upbeat and encouraging interactions. This increases the engagement of group members.

**Self-regulation.** Knowing when you should continue to talk and when you should let others talk is important. You can get your thoughts across, but also allow members to feel like they can participate and engage in the conversation. This allows for increased participation among the group members and also sets a good example for other group members.

**Effective communication.** Planning what you are going to say in advance helps you organize your thoughts before talking. Group members will get a clear picture of your ideas.

**Leadership and confidence.** You are the leader of the group and members are looking to you for guidance. Showing members what they are able to do will increase their own leadership skills and help them take initiative for themselves.

**Behavior management.** Knowing what to do when people disagree or when someone talks too much helps keep the group focused on the topic instead of the communication problem.

**Respect.** TBIs affect people in different ways. Be respectful of the different people who attend the group and work to understand their emotions. Treat others how you want to be treated.

In addition to having these characteristics, you may need to go through a formal process before becoming a facilitator. A sponsoring organization may require an application process, a background check, and/or an interview before being cleared to run a support group.

## BENEFITS FOR FACILITATORS

There are many benefits of being a TBI support group facilitator. Here are some of the advantages that come with leading a group:

**Learning.** Support groups are an opportunity for dynamic learning between the facilitator and the group. Each session will allow members to learn about themselves, each other, the guest speakers, and the facilitator. As a facilitator, you will also learn from the group members and improve your facilitation skills.

**Organization.** You will be in charge of many administrative tasks. This role will help you learn to organize the meetings, assign tasks to other people as needed, and be aware of each aspect of the group.

**Leadership.** Getting in front of a group of people and conducting a meeting takes a lot of courage. Use your role as the leader to keep the group focused and manage group behaviors.

**Confidence.** Support groups can increase your confidence as members get to know each other, feel accepted by the group, and share openly with one another.

**Public Speaking Skills.** Your presentation skills will improve by learning what it takes to lead a group. As a facilitator, your voice clarity, volume, and speed of speech are all factors you can work to develop.

**Growth.** Support groups allow you to recognize the growth you have made. New members may be inspired by what they have seen you accomplish after a brain injury.

### Do facilitators assume other duties?

In some groups the facilitator assumes other leadership responsibilities that are administrative in nature. However, it is often easier to get a facilitator (particularly if the person is a professional) when administrative tasks such as those described in the next section are handled by others.

### Suggestions

1. Discuss how to strengthen the facilitator role in your group. It is recommended that you separate facilitating from other leadership roles and enlist someone experienced in group process (try a social worker, counselor, teacher, or psychologist) to facilitate the group or to train someone else to do so.
2. Locate two or more facilitators so that you can split the large group into subgroups and so there will be alternates when needed.
3. Brainstorm with the group leader to develop some “ground rules” for discussions, such as one speaker at a time, respect each other’s ideas, give everyone a chance to speak, speak only on the topic being discussed. A copy of the ground rules could be displayed at every meeting.

## SUPPORT GROUP 101 – GETTING STARTED

Support groups may be started by individual survivors or family members, interested professionals, friends, or facilities. They may be limited in membership to a certain number or type of participants or open to new members on a continuing basis. Usually, the organizers have an open, community-based, self-help group in mind where members receive and provide mutual support and information in an understanding environment. The following steps briefly outline how this type of group may be started:

**Assess the needs.** Call BIAF for information and for any resources that could assist you; demographics.

**Enlist assistance.** Through phone calls and emails, you will likely find people or organizations willing to help you start your group. Other survivors, caregivers, or members of the BI community can help support your new group and for you as a facilitator. Being able to build a group with other people can be useful for shared responsibility, organization, and planning.

**Schedule a planning meeting.** Hold a meeting with people you have enlisted to start the support group. It can be useful to divide up tasks to help you as your support group starts. Possible roles that could be assigned in your planning meeting include:

- **Facilitator:** Identify a person or persons experienced in handling groups to keep the members on target, to make sure everyone participates, and to help develop topics for group sharing that meets the needs of the members.
- **Facilitators** can “make or break” a group and should, therefore, be familiar with communication styles and techniques, listening skills, dealing with difficult people, and other group process skills. Many health and human service professionals are experienced in this role; however, any individuals who are sensitive to these issues and willing to learn more about facilitating groups could serve in this position.
- **Secretary:** This person would take notes during support group meetings. When establishing this role, work out a plan to protect the confidentiality of group members. For example, the person can take notes in a notebook during the meetings and hand the information back to the facilitator at the end of each meeting to be kept in a secure location. No names will be referenced in the notes.
- **Communications Coordinator:** This person can assist the facilitator in making reminder phone calls to members, e-mails, advertising the meetings, and providing outreach to new members.
- **Back-up Facilitator:** This person can help the facilitator plan the agenda. This person could also facilitate meetings if the regular facilitator cannot be there.

**Decide on a day and time for first meeting.** Meeting once a month on the same day for an hour is a good start. Allow the support group 3-6 months to become established by sticking with the day and time you agree upon. Once your meetings get started, this can be changed to meet the needs of the members.

Consider what will be best for you as a facilitator and the people who have expressed interest in the group. Weekday evenings are helpful for people who work during the day. Weekend mornings or afternoons provide more daylight for those who may not want to travel at night.

**Make a list of possible places to meet.** Generally, it's helpful to search for a location that will be private and comfortable for members. Suggested meeting locations include: hospitals, rehabilitation centers, and disability centers, senior/community centers, coffee houses with quiet meeting rooms, civic organizations such as Kiwanis and Rotary Clubs, YMCAs, and nonprofit organizations libraries, universities, churches, or synagogues.

**Visit meeting locations.** After identifying several possible meeting locations, you will need to contact those facilities. Call or visit the sites to discuss the possibility of your group meeting at the facility.

**Decide on a meeting location.** Do not jump at the first offer of space unless it completely meets your needs. Compare your notes about the different sites you have visited and make a decision based on the best fit of location, day/time, and meeting space.

**Plan first meeting.** Plan a time, place and agenda for the first meeting to find out who would come on a regular basis and who might help with group tasks. Advertise in newspaper community bulletin boards and through facilities above. Obtain educational materials from BIAF.

At the meeting explain the purpose of the group and what you have in mind for a format. Determine the group's preference for a time, frequency, length of a meeting and place for regular meetings. Get names and addresses of all who attend and want to be on a mailing list.

**Appoint volunteers and elected administrative staff.** The administrative tasks to be done for the group are each relatively small and should be shared for a limited time period among those who attend. They include acting as a key contact person, membership coordinator, publicity coordinator, information coordinator, meeting arranger. These tasks may be combined, expanded, renamed, or subdivided as desired by your group. Spreading responsibility among a number of people is important to assure that the group doesn't become "leader-dependent" and rely on one or two people to handle all the administrative details.

**Keep the group going and growing.** People will come and go as their needs are met, but the basic structure should be maintained through a good connection with BIAF, continuing publicity, effective facilitator(s), shared administrative leadership and, above all, close attention to members needs for information and emotional support.

## CREATING A BALANCED SUPPORT GROUP TO MEET MEMBERS' NEEDS

### What is a "balanced" program?

Over the course of a year, a balanced support group should offer time for group sharing and mutual problem solving, assistance in finding answers and resources to address concerns of members, and opportunities to relax and socialize with people who understand.

At any given time, support groups are usually comprised of long-time and newer members; survivors, family members, and professionals; and a range of ages and abilities. Meeting all needs and expectations is an impossible goal, but through periodic surveys and discussions of problems members face, topics and programs of most interest will become clear.

Remember, losing members is not always a sign of failure. It can be that people's needs have been met for the time being and they have moved on.

### Conducting the first meeting

The first meeting can be stressful. You may not know how many people will come or what to expect. It can take a few meetings to get comfortable and to build up membership. Breathe, keep your first meeting simple. Gather educational materials or materials to run group efficiently. These could include:

- A sign to direct participants to the meeting room
- A greeter at the entrance to the building to welcome people and provide direction
- Name tags - consider using reusable ones to save on expenses
- Pens or markers for people to write their names on nametags
- Handouts of agenda or materials that will be discussed
- Sign-in sheets (*see page 26*)
- Refreshments, if your budget allows but do not overestimate the first meeting, plan for 10 or fewer

Arrive early. When you get to the meeting location, arrange the room and set up materials. If possible, arrange chairs in a circle to encourage group participation. Greet each member. Welcome people as they arrive and thank them for coming. Point out the name tags and sign-in sheet. Begin the meeting. Ask everyone to take a seat. Request that everyone turns off their cell phones or puts them on vibrate or silent.

Introduce yourself as the facilitator. Explain who you are as a facilitator and share why you have elected to start a support group, allow yourself to be open and honest. Tell the group the role of a facilitator and explain how a support group functions. Share your hopes for how you see the group being helpful and meaningful. Introduce the group members or ask each person to

take a turn and introduce themselves and why they are attending the meeting. You can consider asking them to share their hopes for attending a group and what personal experience they have with brain injury. Remember, if someone chooses not to participate that is okay, they may need some time feel comfortable before sharing. Set limits on the amount of time that is allowed per person to share so that each person can have a turn.

Encourage everyone to sign-in each meeting, but assure them that their information will not be shared. Establish ground rules. When setting the ground rules be sure to stress that things shared in group, is shared in confidence. Suggest basic rules to help meetings run smoothly. These can be simple and can be placed on a board for everyone to see. Like starting meetings on time, respecting others, keep comments brief, and listening without interrupting. Take a vote as a group to decide on the rules your group wants to follow and add them to your list.

You may choose to start off with an icebreaker, a simple activity. The activity should last no longer than 5-10 minutes. This is a good opportunity for members to learn about each other and their group.

Be sure to allow for breaks, approximately 10 minutes. If group lasts for two hours there should be a break to allow for bathroom breaks and to stretch their legs. Work together to brainstorm about ideas for future meetings. The members may have specific items they wish to learn more about. What do the members want out of future meetings? Are they more interested in sharing personal experiences or having speakers? Do they want to have a social component to the group? What needs do they hope to meet with these meetings? Write down everyone's suggestions, butcher block paper is great so that the ideas can be captured and the facilitator can take them and turn them in to working documents. Make sure every member knows that their ideas and input is valuable to the group. Share the next topic that will be discussed at the next meeting. Share your contact information and the BIAF RF Program with members. Remind the group of the date, time, and location for the next meeting, if the meeting location changes, it is good idea to send them home with a flyer or reminder with the address. Be sure to ask them to add their contact information to the sign-in sheet. Let members know that you will contact them via e-mail, mail, or phone to remind them of the next meeting. Now would be a good time to ask for a volunteer to help with sending out reminder information for future meetings. Thank the participants for coming and close the meeting. Make yourself available for questions, it is nice to ask for a BIAF Resource Facilitator to be present to address additional concerns or resources. Allow time for socialization, 10-15 minutes following the meeting allows time for members to share personally with each other or to ask questions. See page 29 for a Sample Meeting Agenda.

Prior to the meeting:

- Arrive early and prepare the room, arrange table and chairs to encourage participation
- Sign-In Sheets
- Pens and Paper
- Name Tags
- Prepare handouts or agenda's
- Prepare refreshments
- Signs directing to meeting location
- Greet each member as they enter the room
- Set ground rules, turn off cell phones or turn them to vibrate, start on time, keep comments brief, do not interrupt and respect others who are sharing
- Discuss confidentiality, what is shared in group stays in group

### What meeting formats are most successful?

Most support groups meet on a monthly basis for one and one-half or two hours, using a regular format that they have found to be effective. Some rotate or combine the formats below within the same meeting. Others use different formats at different meetings. In any case, it is a good idea to establish a pattern to follow for the year, providing a consistent mixture of group support, education, and socialization.

- **GROUP SUPPORT** – While a designated topic may be selected for the evening, the meeting usually begins with a “round robin” sharing of personal experiences related to the topic. This is followed by a discussion and exchange of ideas where people find “answers” and encouragement from experiences of others. It is a good idea to establish the topic for the next discussion from interest and problems the members bring up during the current meeting. Groups with over ten or twelve members are considered large for discussion and many choose to subdivide: one group for survivors and another for families and caregivers.
- **EDUCATIONAL/INFORMATIONAL** – Most groups set aside time for education at their meetings and invite expert speakers, show and discuss videos, or have their member's present information on topics of interest. A list of possible topics should be developed, using ideas from members, other support groups, BIAF, or this guide, so members can be on the lookout for possible speakers. Often the educational meetings are offered quarterly or on alternate months.
- **SOCIAL/RECREATIONAL** – This format provides opportunities for people to interact socially and informally get to know each other. Parties, potlucks, table games, or any fun activities members are willing to organize can meet important needs and provide relief from daily struggles.

### Suggestions

Inviting a guest speaker can bring in a new perspective and allow for a subject matter expert. A guest speaker may or may not be a professional who works with people who have a BI.

When choosing a guest speaker, make sure his or her information will be helpful and that the members can take something away from the subject matter that they can apply. The speaker should NOT be there to sell a product. Guest speakers may address new products or treatment methods that have been found to be helpful, example the Center for Independent Living may have items to help with time management or origination skills. You may be approached by someone who wishes to speak to your group. A group may express a desire to have someone talk to the group on a particular subject. As facilitator, it is your responsibility to choose an appropriate speaker or assign a group member to the task. Both your support group and the chosen speaker should be given a copy of your Speaker Disclaimer prior to the presentation.

Here are ideas of possible speakers:

- Medical Professionals
- Neurologist
- Psychologist
- Nurse specialist
- Physical therapist
- Occupational therapist
- Speech pathologist
- Recreation therapist
- Pharmacist
- Dietician
- Exercise physiologist
- Community Health Professionals
- Social worker
- Representative from county office on aging
- Adult day care or nursing home staff
- Hospital or nursing home chaplain
- Community Arts and Leisure Professional
- Speaker from a local museum or historical site
- Dancing or music instructor
- A local artist
- Computer teacher willing to teach adaptive computer techniques
- Poetry
- Community Professionals

- Attorney
- Owner of a local medical equipment company
- One of your own members who has had a recent adventure, publication, art show, or has traveled

Topics requiring quest speakers

- “State or Federal Programs that Benefit Persons with Brain Injuries”  
Speaker: Representative from the nearest State or Federal offices.
- “Sexuality and Intimate Relationships”  
Speaker: Sex educator or experienced social worker.
- “Driving after Head Injury”  
Speaker: Certified driving education specialist.
- “Life Transitions after Brain Injury”  
Speaker: licensed clinical social worker, mental health or grief/bereavement counselor.
- “Community Re-Entry: What Does it Mean?”  
Speaker: Professional Operating a Community Re-Entry Program.
- “Understanding Behavior Management”  
Speaker: Neuropsychologist or Behavior Specialist in Brain Injury Program.
- “What is a Cognitive Rehabilitation?”  
Speaker: Neuropsychologist.
- “Pharmacological Treatment Subsequent to Brain Injury”  
Speaker: Hospital-Based Pharmacist or Neurologist.
- “Substance Abuse after a Brain Injury”  
Speaker: Psychiatrist, Neuropsychiatrist, or Neuropsychologist actively involved in successfully treating this problem. Usually AA counselors are unfamiliar with the cognitive deficits that prevent successful rehabilitation of abusers.
- “Use of Leisure Time”  
Speaker: Recreational Therapist

- “Discharge Planning, Where Do I Go From Here?”  
Speaker: Case manager from rehab facility, and if available in the area, a case manager or discharge planner from a post-acute program.
- “Legal Issues after Brain Injury”  
Speaker: A local personal injury attorney (call state resource office for recommendation in the area).

### Panel Discussions

Use attendees as members of panels, and a moderator to facilitate the discussion. Panels should have from three to five panelists and a list of questions should be given to panelists in advance. Not all questions are usually used, but it helps panelists feel more prepared.

- “Effects of Brain Injury on Family Relationships” use panel composed of couples (one of whom is the survivor), siblings of survivor, or parents
- “After Brain Injury: What Do I Do Now?” survivor panel
- “Everything You Ever Wanted to Know About Brain Injury” use a mixed panel of parents or spouses whose survivor is in the early stages, one in rehab, one in transitional stage, and one whose recovery has permitted re-entry into the community

### Interactive Sessions

Use recreational therapists or others experienced with the topic and in working with people with disabilities.

- Self-expression through music, art, poetry, dance, or creative writing
- Tai Chi
- Stress reduction and relaxation techniques
- Dating and making friends (try role-playing)
- Hobby-sharing night
- Being an advocate – writing your legislators and policy makers

Consider speakers on topics of general interest such as financial management, use of computers, motivation, assertiveness or humor. Sometimes a local Toastmasters Club or a Speakers Bureau can provide ideas.

Sometimes members find it difficult to come up with topics that might interest them. Try this: ask members to share one or two goals (small or large) that they personally hope to accomplish during the year. Make a group list. Discuss what information might be useful to help reach these goals and whether there are common interests that could be discussed at future meetings.

What should be done if questions arise that cannot be answered by anyone present?

From time to time, questions arise in support group meetings that cannot be answered at that time. The leader or an appointed person should be responsible for writing down the question and the name of person requesting the information and assigning someone to seek an answer. The answer may be found through BIAF Resource Facilitation Program, local experts, available publications or other means. Other techniques for responding to questions may be employed as long as there is a procedure for helping people with accurate and timely answers.

At your meetings, make a special point to make new members feel welcome.

Promoting involvement in the group is not just getting individual to their first meeting...they must want to come back.

- Have a greeter meet them at the door and help them register
- Provide name tags and ask others to wear name tags
- Introduce them to a few people before the meeting starts and let them know what will happen
- Encourage them to return and/or to contact you for further information
- Follow-up call to thank them for coming and ask them to attend the next meeting

## **PUBLICIZING THE SUPPORT GROUP**

### *How do you attract prospective members?*

If you want your group to be a community resource open to new members someone will need to be responsible for routinely publicizing the group's existence. Put a regular announcement in as many of the places below as you can each month. The announcements should state the name of the group, contact person and a phone number, meeting time and place, and who is invited (i.e. professionals and agency personnel as well as survivors and families).

- The local hospital social service department
- Rehabilitation facility and community calendars
- Veterans Administration hospitals
- Non-profit sections of most community newspapers where support groups list schedules
- Local cable TV "bulletin boards"
- Local offices of state vocational rehabilitation, human resources, public health, Developmental Disabilities and Social Security
- Offices of local professionals who work with survivors of brain injury and their families
- Ask if hospitals, community centers, religious institutions, BIAF or civic organizations will consider advertising in their newsletters and websites

### *Publicizing through social media*

We know that individuals are now turning to the internet for information, creating a website specific to your local support group, meeting times, locations and activities is a great way to meet the needs of survivors, caregivers and professionals in your community. You may also want to consider advertising your group meeting times on locations on:

- Craigslist.com, under groups or activities
- Community online calendars: Chamber of Commerce, local clinics and hospitals
- Facebook and Twitter
- Brain Injury Association of Florida

### *Public service announcements and media*

Talk to local radio and TV stations about announcing your meetings. Non-profit groups can often submit 30 or 60 second announcements for no charge (Public Service Announcements "PSA").

If you feel you have a particularly compelling story to tell the newspapers, discuss your thoughts with BIAF and get their guidance and suggestions in approaching your local paper and publicizing the case. Perhaps a letter to the editor would be helpful in some instances.

Make an effort to publicize special speakers or occasions (such as Brain Injury Awareness Month in March) in other sections of the local newspaper than the usual announcements. The papers will be happy to tell you exactly where to send your information.

Do not be frustrated if your first meeting is not well attended. As long as you are reaching out, it is the beginning to a successful support group. Many existing groups started with three or less participants and have grown into large groups over time.

Publicizing the group never ends, even when you have a large gathering. You will still need to continue to send out a press release when you have a speaker or specific topics for the group. If attendance starts to decline, you may need to review your publicity efforts to attract new members.

It is important to maintain good relationships with your media contacts. Ask your members if they are comfortable inviting a person from the media to attend one of the meetings. This way, the media can learn more about your group and about TBI. This may lead to a human interest story and even more attention for your group.

Create and distribute flyers to local organizations, medical facilities and individuals. Your flyer should include all information about your group. The flyer should be simple and easy to read, enough information without overwhelming and individual. A sample flyer can be found on page 31.

Consider posting flyers at the locations listed below to reach your largest demographics:

- Hospitals
- Doctor's offices
- Rehabilitation facilities
- Health and human services providers
- Churches, synagogues, and mosques
- Community and senior centers
- College campuses
- Civic organizations
- Coffee shops, bookstores, and libraries

## GOOD CONNECTION TO THE STATE ASSOCIATION

### Why is it important to know about the state and local organizations?

Members of support groups should understand how they are connected to an entire organization that is dedicated to helping them. People come to support groups to be reassured they're not alone! It helps to know that work is going on at all levels to benefit the members. Inform the group that:

#### *Brain Injury Association of Florida, Inc.*

Acts as a clearinghouse for information and resources; advocates for major changes in the state system; works on large programs and statewide public awareness; Information and Resource Facilitation program. BIAF also provide an Outreach Team to assist in providing guidance and support to each support group within the state.

#### *Local Support Group*

Provides personal support and information to individual survivors and families; assures people they are not alone, and directs them to sources of appropriate information.

### How can we all work as a team?

Communication is essential. Work with the Brain Injury Association of Florida to establish the best ways to communicate. BIAF's Staff is available to provide guidance on newsletters, meetings, teleconference calls, monthly reporting, and regional conferences, which all can be effective. Tell the BIAF office what you need. Find out about and USE whatever resources they can provide.

### Suggestions

1. Dedicate time at all meetings or at least one meeting a year to a discussion of how the Brain Injury Association of Florida (BIAF) works on behalf of the individual survivor and family.
2. Have BIAF e-newsletters on hand at every meeting.
3. Mention at meetings and in your meeting announcements that the group is affiliated with BIAF, and provide the phone numbers for contacting these organizations for further information or assistance.
4. Keep BIAF informed about the group's activities and progress through photos and articles for the state e-newsletter, or letters from members.

## **DIVIDING THE WORK AND ASSIGNING KEY ROLES**

No matter what your group structure may be, there are certain tasks that most successful support groups must have done. These jobs (listed below) may be combined, expanded, renamed, or subdivided even further. Whatever suits your group will work as long as the job is covered. They are not major IF everyone helps. The important thing is that one or two people don't get stuck with all the jobs, and that people do not become "burned out" from their efforts. Other jobs may be necessary depending on the additional roles the group has undertaken.

- **GROUP LEADER** – coordinates efforts of others; assigns tasks as necessary; obtains speakers group wants; represents group at meetings; is liaison to BIAF and sponsoring organizations when applicable; assures there are periodic evaluations of meetings.
- **KEY CONTACT PERSON** – willing to have phone number widely published; gives first impression by phone; is "point of contact" (not a problem solver) for all seeking information; encourages potential support group members: can refer callers to appropriate sources of information.
- **FACILITATOR** – facilitates support group; keeps group on target; helps group develop future meeting topics; skilled in group process.
- **MEMBERSHIP COORDINATOR** – keeps current list of names and addresses; prepares and sends meeting reminders; encourages state association membership; "registers" new support group members at meetings; preferable has access to computer to keep membership database.
- **PUBLICITY COORDINATOR** – assures meeting announcements are in newspapers and other places; writes reports and newsletters. Manages website and social media.
- **INFORMATION COORDINATOR** – assures that printed handouts and brain injury information are available at meetings.
- **MEETING ARRANGER** – assures room and other arrangements are made, such as refreshments, chair and table arrangements, clean-up, and speaker's equipment.

### How do the groups become dependent on one or two people?

In the early stages of a new group, the group members often look to one or two people to perform all leadership functions. Tasks seem to be done more efficiently and accurately that way, and the leaders readily accept their pivotal role. As the group matures, however, members should be expected to share responsibility for the group's success. If this doesn't happen, the group often becomes leader-dependent, and it is increasingly more difficult to persuade other members to accept responsibilities. It can be done, however, if the original leaders are willing to turn over the results of their long-standing efforts to others who are less experienced, and if suggestions provided on the following page are put in place.

### How can we get people to accept jobs and perform them effectively?

People are usually open to accepting jobs IF they feel that (1) they have the time and ability, (2) what they'll be doing is needed and important, (3) their efforts will be valued and appreciated, and (4) they know exactly what is expected of them.

### Suggestions

1. Have yearly elections.
2. Give each person a copy of his/her "job description." It can be as short as the descriptions on the preceding pages or it can be more specific in spelling out exactly what must be done each month. It will be a helpful guide to those who accept the job as well as to those who may otherwise interpret the job differently from what the group intended.
3. Establish a trial period for every job (3-6 months) to let people decide whether they can continue or want to continue. Make it perfectly okay for people to let the group know they cannot or do not wish to continue, as long as they give advance notice
4. Set definite terms for each job, whereby individuals don't have the same job year after year without a break.
5. At least once a year give special recognition to those who have served. You can't say "thank you" enough!
6. Designate or encourage "back-ups" or "co-workers" for each job so people can help each other.
7. Get the facilitator or experienced social worker to lead a group discussion on what to do if someone is not performing his/her tasks satisfactorily. If possible, do this BEFORE problems occur. Put the thoughts in writing and keep on file. Review these thoughts whenever new people are selected.

## SPONSORING ORGANIZATION(S)

### What should the role of a sponsor be?

The ideal role of a sponsor or sponsors is to underwrite the costs needed, resources and to help guide the group without assuming total responsibility for and leadership of the group. It is often very helpful for two or three facilities to share in providing the support mentioned above.

Primary services often provided include:

- Meeting room space
- Mailing services/postage
- Audiovisual equipment
- Coffee and refreshments (optional)
- Access to phones, computers, and fax machine
- Office/secretarial supplies

Although facilities and professional staff can be instrumental in creating a group, *it is important that members themselves develop a sense of responsibility and ownership.* Otherwise, the group becomes dependent on the professionals involved and the concepts of self-help and mutual support may get lost.

### How does a group find sponsors?

Many times organizations are like people when it comes to accepting responsibilities. They like to know exactly what you want and for how long. It may help in this case to have your request limited to a certain time frame (six months to a year) and to have potential sponsors select from the items above what they would be willing or able to provide. As both parties get to know each other, the relationship may expand – especially if you remember to say thank-you often and to recognize and acknowledge their contribution.

Care should be taken to ensure that all brain injury programs and facilities in the support group area are equally acknowledged, and the leader should curtail any efforts to market individual services. Along the same line, the names and addresses of the group members and the group mailing list should never be used for marketing purposes and, in fact, should not be given to anyone outside the Brain Injury Association of Florida for any propose without the permission of the individuals on the list.

Confidentiality and privacy are an important issue for all groups. This means that any information that might individually identify a group member should not be released outside the group, verbally or in a written or pictorial form. A good rule to remember is “what is said or done at a meeting should not leave the meeting.”

### Suggestions

1. Make a list of the items that your group needs before contacting potential sponsors.
2. Explore how other self-help groups, which are listed in your local newspapers, relate to sponsoring facilities/professionals.
3. Meet with current or potential sponsor(s) to discuss what services they might provide to your group and for how long. Be sure to acknowledge the sponsors' help with a written thank you, in meeting notices, newsletters, or in any other way possible.
4. Consider going to the sponsor for use of facility for printing, faxing and copies. Churches and local community centers are potential resources for in-kind time and use of facilities.
5. Sign a written agreement stating what the sponsor provides and what the support group will do, to avoid confusion or misunderstanding about the role of each party.

## PRINTED MATERIALS

### What is the best way to assure members are getting information they need?

Getting needed and desired information to group members is one of the major goals of a support group. In most successful groups it is an area that receives attention at each meeting. The information coordinator, leader, and facilitator can all work together to:

- Determine through group discussions, surveys, and problem-solving time what information the members need and have to share
- Seek accurate sources for this information through guest speakers, videos, or printed materials
- Encourage members to share with each other what they have learned or what printed material they have obtained
- Supply resources for obtaining more in-depth information about any particular problems that group members face
- Try to have some informative materials photocopied and displayed at each meeting. Contact the BIAF for materials pertaining to the evening's topic, or other general information
- Arrange to make copies of materials that members want, or know where others can get copies. Refer to [www.byyourside.org](http://www.byyourside.org) for a list of available educational and informational materials

Group members need to be encouraged to become involved in this important component of the program and letting the information coordinator know what is helpful. Otherwise, a few people may be trying to “second guess” what the others want and written handouts may just go to waste.

### Suggestions

1. Determine with the help of the group what printed materials should be regularly available at each meeting. Encourage people to take only what they will really use or read.
2. Have the information Coordinator or other volunteer review a book or video that is available through BIAF or by visiting [www.byyourside.org](http://www.byyourside.org) , and report on it briefly to the group. Let members know how they can obtain it, if desired.

## ANNUAL EVALUATIONS

### Why is evaluation important?

Asking people for honest feedback about the various aspects of the group and acting upon that feedback can be the most effective way to retain membership.

### What are some evaluation techniques to use with the group?

Evaluation means that you use some technique (it doesn't have to be fancy) to find out how people honestly feel about the group. It is very important that it not be presented as a negative process. Identifying strengths and building on them is more valuable sometimes than focusing on "weaknesses". In all cases, evaluation should be constructive and all members should take responsibility for acting upon results. Listed below are some techniques the group might consider.

#### 1. *Survey*

Yearly you may choose to do an interactive survey or provide a paper copy.

Questions should address the time and location, best and worst practices. An Example evaluation form can be referred to on page 29.

#### 2. *Set goals to improve group meetings*

With your leaders and/or the entire group, visualize and put in writing on a flip chart what the members think "being successful" means to your group in each area of this guide. Set goals for the year to improve the group's effectiveness and then talk about how you will reach the goals. This method avoids discussing past problems and focusses on the future.

## RAISING MONEY

What about raising funds for special projects or scholarships to conferences? If your fund-raising idea is not part of an overall plan sponsored by a 501©3/Non-Profit, the best advice is: BE CAREFUL!! Especially if you plan to approach the public, rather than target just your own members and their families and friends. The IRS has fund-raising rules. The State may have solicitation regulations. The larger non-profits have auditors and accountants which have standard, acceptable practices for keeping track of funds. If you are not aware of what rules apply to your group, you may unknowingly create serious financial or legal problems for your members. Check with your state association moving ahead with any fund-raising plans.

### Possible Expenses and Revenue

You may or may not need to be concerned about all of these expenses or income sources, but these are the basics:

Group Meeting Costs:	Food/beverages, room rental
Ongoing Material Costs:	Paper, copying, postage
Ongoing Administrative Costs:	Advertising, insurance/liability 501©3
Other Possible Costs:	Cleaning supplies, field trips or social activities, fees for guest speakers, support group facilitator stipend, phone service
Possible Revenue:	Donations from support group members and sponsors, fundraisers, organization dues

\*Don't forget to first check into sponsors and In-Kind donations.

The BIAF can provide all educational and informational pamphlets, books and DVD's.

## **RECORD KEEPING USABLE FORMS and FLYERS**

**Contact log:** Use this log when you talk to people who either would like to help start or be a member of the group. It can be used to keep track of group members, speakers, caregivers, and anyone else related to the group.

**Sign- in sheet:** Use these sheets to keep track of attendance at each group. Use this sheet to create and update email lists, phone lists, or mailing labels to remind members of the next meeting or to send important information.

**Meeting preparation checklist:** This is a good reminder of the steps to keep in mind before each meeting.

**Sample agenda:** This is an example of a handout that can be given to the group. It can be helpful to make your own version of this form to use for each meeting. It can be a reminder to stay on track if you get nervous in front of groups or as a prompt for the next step.

**Evaluation and Feedback Form:** Give this questionnaire to new members at the end of attending their first group. Explain that they can fill it out and return it directly to you. Reassure the members you will keep their information confidential. It will provide feedback and help you learn more about their interests.

**Support Group Flyer:** Create and distribute flyers to local organizations, medical facilities and individuals. Your flyer should include all information about your group. The flyer should be simple and easy to read, enough information without being overwhelming.

## TBI Support Group CONTACT LOG

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/State: \_\_\_\_\_ Zip: \_\_\_\_\_

E-mail \_\_\_\_\_

Home Phone: \_\_\_\_\_

Cell Phone: \_\_\_\_\_

Interest: \_\_\_\_\_

Other: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/State: \_\_\_\_\_ Zip: \_\_\_\_\_

E-mail \_\_\_\_\_

Home Phone: \_\_\_\_\_

Cell Phone: \_\_\_\_\_

Interest: \_\_\_\_\_

Other: \_\_\_\_\_



# TBI Support Group MEETING PREPARATION CHECKLIST

Questions:

Notes:

Is there a cost to use the meeting room? If yes, what is the cost?	
What day and time is the room available?	
Are tables and chairs provided? If yes, who will set them up?	
How many people will the room hold if some are in wheelchairs?	
Is the entire building accessible to walkers and wheelchairs as required by ADA (Americans with Disabilities Act) standards?	
Is the lighting appropriate for individuals with light sensitivity challenges?	
Will doors keep the outside noise from disrupting the group?	
Are the bathrooms located near the meeting room?	
Could you gain access to the building on nights and weekends?	
Will there be staff in the building?	
Is the parking safe and convenient with a “drop-off” place at the door nearest to the meeting room?	
Is there a telephone accessible at all times?	
Who is the contact person and how can he or she be reached during off hours?	
Is liability Insurance required?	
Is there a kitchen available? Coffee pot?	
What audio visual equipment is available?	
Is there a closet where the group can store supplies and literature?	
Would the facility be willing to advertise your group there?	

# TBI Support Group

## SAMPLE MEETING AGENDA

### SAMPLE MEETING AGENDA

#### Introductions (5 – 10 minute)

If everyone knows everyone, just remind people of your name. New members get extra time to tell their story.

#### Information Sharing (20 – 45 minutes)

Members are encouraged to clip stories from newspapers or health newsletters to share information learned from personal reading and experiences, or to ask questions of professionals who may be present as general resources. If a quest speaker is present give 20-30 minutes for presentation and 10–15 minutes for questions.

#### Separate Support Groups (50 – 60 minutes)

Survivors and families separate and, with help of facilitators, proceed with group sharing and problem solving around topic(s) of interest. Professionals and friends who attend usually go to the family group.

#### Wrap Up (5 – 10 minutes)

Whole group reconvenes for any last-minute questions or announcements.

\*The evening ends with an informal “meet-and-greet” time when members can exchange phone numbers, make dates for extra get-togethers or ask specific questions of leaders, professionals or each other.

# TBI Support Group EVALUATION AND FEEDBACK FORM

Facilitator:

Date:

Please fill out this form and return it to your facilitator.

Name: (optional) \_\_\_\_\_

Phone Number: (optional) \_\_\_\_\_

What is your favorite thing about this group?

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What is your least favorite thing about this group?

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How effective is the facilitator at leading the meetings?

Very Effective

Somewhat Effective

Not Effective

Comments:

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How can this support group be improved?

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Additional comments, suggestions, questions or concerns:

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Thank you for your feedback!

## TBI Support Group SAMPLE FLYER

Create your own, or ask someone else to create a flyer for your group.  
Make it eye-catching and creative, but not too busy.  
Be sure to include all relevant information about your group.

### Traumatic Brain Injury Support Group

Join a great group as we gather together to share about life with a traumatic brain injury. We discuss resources and education, plus support each other in our journey of recovery.

Where: Local Community Center  
22 Main Street, Anytown, 55555

When: The first Monday of each month  
7:00 pm – 8:30 pm

Questions: Call Jane Doe at (555) 555- 5555 or e-mail at [jane@email.com](mailto:jane@email.com)

Hope to see you there!

## CONCLUSION

The components and suggestions in this guide are intended as a helping checklist, not as a rulebook. The most important factor to keep in mind is that the purpose of the group is to meet the needs of the individuals who attend. Efforts should be made on a consistent basis to find out what these needs are and how the group might meet them. The group can then provide information and support that will be educational, reassuring, and useful in helping survivors and their families rebuild productive, meaningful lives.

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