HELPING OURSELVES

A Guide for Brain Injury Support/Recovery Groups
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This manual is intended to aid in the development and maintenance of local support groups and - as such - belongs to the group, not any individual. The Brain Injury Association of Virginia (BIAV) requests that if the facilitator/leader who received this manual leaves the group, the manual gets passed on to the next facilitator. Thank you.
Purpose

Over the years, support groups have been organized across the state; some taking advantage of the Brain Injury Association of Virginia (BIAV) and its resources, some operated and organized by brain injury service providers, and some independently providing comfort and company for each other.

Our goals with this manual are to help these groups plan, start, and run a successful support/recovery group that addresses their specific needs and unique qualities; empower them to maximize their effectiveness; and inform them of all the resources available through the Brain Injury Association of Virginia.

We recognize there will be two different audiences for this resource: those who are starting a support group for the first time and those leading an established group. New and old support groups can benefit from reviewing the entire guide, as there are areas of overlap between the issues both groups need to consider.

Acknowledgements

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General Information
The Brain Injury Association of Virginia

Mission: To create a better future for Virginians through brain injury prevention, research, education, advocacy, and support.

Guiding Principles:
- Compassionate assistance that respects the dignity of those we serve
- Proactive leadership that advances progressive and innovative public policy
- Diligent collaboration and cooperation with the brain injury community
- Integrity and trust in our operations and relationships

Vision: A world where all preventable brain injuries are prevented, all unpreventable brain injuries are minimized, and all individuals who have experienced brain injury maximize their quality of life.

History: The Brain Injury Association of Virginia (BIAV) was founded as the Virginia Head Injury Foundation in 1983 by families who were struggling to face the aftermath of brain injury. Our name changed to the Brain Injury Association of Virginia in 1995, and today BIAV is the primary source of information and personal support for thousands of individuals, families, and professionals living in Virginia whose lives have been touched by a life-altering, often devastating, brain injury. We are a non-profit organization with over 25 years of experience serving persons with brain injury, family caregivers, human service professionals, state agencies, elected and appointed policymakers, and other key stakeholders. BIAV has provided information to more than 250,000 individuals and individualized assistance to over 20,000 people. As a state affiliate of the Brain Injury Association of America, we are part of a national network that serves over 100,000 people each year.

Scope of Services

- **Education** - BIAV has an extensive clearinghouse of information about brain injury, has compiled and created resources and reference manuals, and conducted or participated in conferences and trainings across Virginia and the United States for persons with brain injuries, family caregivers, and professionals.
- **Outreach and Family Support** - BIAV operates a toll-free Family Help Line, provides information and referral services for people with brain injury, conducts outreach to newly injured Virginians, and offers technical assistance to a cadre of statewide support groups. Regional offices in Northern Neck/Middle Peninsula, Piedmont, and Northern Shenandoah Valley serve local communities. BIAV also provides the largest and longest running brain injury camp program in the U.S; Camp Bruce McCoy is a two week residential recreational program for adults with brain injury.
- **Public Awareness** - BIAV publishes a quarterly newsletter, conducts an annual awareness campaign for Brain Injury Awareness Month, is involved in a variety of public awareness activities, and works collaboratively with other organizations to raise awareness of and prevent brain injury.
- **Advocacy** - BIAV promotes, guards, and advances the rights of people with brain injury. We represent the interests of the brain injury community on state agency workgroups and taskforces, work with elected and appointed policymakers to improve funding and services, and teach persons with brain injuries and family members how to advocate for their needs.
Quick Reference: What BIAV Can Do For Your Group

BIAV can:

- Be your first point of contact for information and ongoing support through their toll free family helpline (1-800-444-6443) and assist with both general information and specific requests. You can also email BIAV at info@biav.net.
- Provide you with information regarding other support groups in your area or people seeking to join a support group like the one you plan to start.
- Answer any questions and help you solve any problems you may have regarding your support group.
- Provide a website with information about brain injury, prevention and awareness, legislative updates and information, and a list of support groups across the state.
- Make this guide available for support group leaders and include you in statewide support leader training sessions.
- Connect you with other support group leaders and brain injury professionals.
- Provide you with printed informational materials and handouts for your group.
- Offer suggestions for topics of interest and suggest possible speakers for your meetings.
- Help answer questions posed by members of your support group.
- Inform you of the latest developments regarding brain injury legislation in the state of Virginia.
- Provide you with brain injury awareness materials and prevention tips.
- Train persons with brain injury, family members, and professionals how to advocate for their needs.
- Provide you with information on Camp Bruce McCoy, the largest and longest running brain injury camp in the US.
- Inform you about the next BIAV conference.
Helpful Definitions & Clarifications

For the purposes of the discussions in this guide, here are some definitions:

**Brain Injury** – Many different terms are used interchangeably for brain injury; these may include:
- Acquired brain injury (ABI)
- Traumatic brain injury (TBI)
- Head injury
- Concussion
- Shaken baby syndrome

Regardless of how a brain injury is acquired, it is classified as either traumatic or non-traumatic.
- **A traumatic brain injury** is an insult to the brain, not of a degenerative or congenital nature, that may result in an impairment of cognitive abilities, physical functioning, and/or disturbance of behavioral or emotional functioning. It may be caused by a blow to the head that is severe enough to cause bruising, bleeding, swelling, or shearing. Common causes of traumatic brain injury include falls, motor vehicle accidents, and assaults.
- **Non-traumatic brain injuries**, often referred to as acquired brain injuries, result from internal causes such as strokes, brain tumors, anoxia, and drug abuse.

**Caregiver** – For the purpose of this manual, the term “caregiver” refers to a family/significant other caregiver rather than a hired or volunteer caregiver.

**Recovery Group** – Some groups operate with more formality and have information sharing as a central focus with friendships and support that evolve out of interaction in the group.

**Brain Injury Support Group** – A support group is a gathering of people who have experienced brain injury (either first-hand or second-hand, such as a family member/significant other) who come together for self expression and encouragement. The group provides a forum for emotional expression within a nurturing environment. Personal expression and mutual support are the seeds of the group; coping and enhanced recovery are the fruits. Meetings are structured to the members’ unique origins, needs, and focus. The support group is about people building each other up and mutual acceptance is a critical component.

**A brain injury support group is NOT:**
- a recreation program, an educational program, or an advocacy organization. When a support group meets for these and/or other purposes, opportunities for self-expression and emotional support are diminished and members do not get what they need to cope with the ongoing trials of brain injury. These extraneous activities can dilute the mission of the group and the original reason for coming together (brain injury).
- a formal therapy session. Many individuals with brain injury often need and participate in some form of therapy. Therapy involves a formal structure, professional direction, confrontation, goal attainment, and the pain that often accompanies self-discovery. While a brain injury support group is not a formal therapy group, it can have a therapeutic effect on the members. The process is not necessarily goal or time limited. A peer driven group with light handed facilitation differs from a therapist’s formal direction.
Benefits of a Support Group

Specific benefits include:

- **Emotional healing** through interpersonal contact.
- **Decrease in isolation and a sense of empowerment** through sharing of experiences.
- **Encouragement** from learning about the achievements of others who have overcome similar difficulties.
- **A sense of usefulness and meaning** by contributing at meetings.
- **Education** from the exchange of information and personal experiences.
- **Socialization** through the establishment and maintenance of important connections with people.
- **Self-awareness** through opportunities to talk about one's injury and feelings.
- **Confidence building** from working on the problems all members have in common.
- **A sense of safety**, in the context of a confidential, supportive, non-judgmental environment, allowing for honest self-expression.
- **A sense of growth** as long-term members see new participants and reminisce about where they began and how far they have come in their personal journey.

A support group can:

- provide social interaction
- educate
- offer respite
Starting A New Support Group
Advanced Planning

Be Patient!

Plan Ahead!

Before starting, read this entire manual to acquire the “big picture.” Excellent planning before the first group meeting will increase the likelihood that the support group will thrive and successfully meet challenges.

Enlist help - Anyone starting a group should first enlist the assistance of a few other people, so these founding members can team up in a spirit of mutual collaboration and divide the work.

Call BIAV and let them know you are starting a support group. You will receive assistance and valuable advice right away. They may even know of other people nearby that want to start a group or that have established a group.
Issues to Consider Up Front

1) Designate a Coordinator and Facilitator

Questions to address before the first meeting:
- Who will serve as the coordinator of the group?
- Can the leadership be shared?
- Would a professional facilitator be best for the group? (Consider that this may enhance the effectiveness of the group discussion.)
- If not, what training might benefit a facilitator? (See “Leadership and Facilitation” section for in-depth information and guidelines.)

2) Determine the Role of Brain Injury Professionals

Brain injury professionals provide:
- Strong organizational skills to plan and conduct meetings.
- Strong facilitation skills to conduct effective meetings.
- Knowledge of the causes and repercussions of brain injury and the impact on families.
- Knowledge and information regarding the systems that persons with brain injuries must navigate (government, healthcare systems, etc.).
- Connections to community resources and other professionals (lawyers, doctors, etc.).

Some groups do not include brain injury professionals. Reasons for this include:
- The support group is established for people who have experienced brain injury on a personal level.
- The support group is based on the assumption that people with similar experiences are the best at helping each other.
- Support group members must feel free to express their feelings, even if some feelings are negative towards professionals.
- Support group members need to feel that there are no ulterior motives in the professional’s involvement in the group (i.e., solicitation, referrals).

There is no right or wrong approach here; choices depend upon the participants’ preferences and opinions about professionals as well as the availability of an appropriate and willing professional.
3) **Identify Group Purpose (Who does it serve?)**

- **Be specific:** The purpose of the group will determine membership, leadership, time, location, etc. For example, is the group open to people with any type of neurologic impairment? Is this a group for parents of children with TBI? Is the group only for caregivers? Group members will have more in common when sharing experiences if the group is carefully defined.

*Become familiar with your area and keep in mind that groups that are too narrow in their definition may lose potential members or struggle to get off the ground. Often, the people who actually show up to the meeting help decide who this group will serve.*

- **Clarify focus:** As a group, draft up a group focus and tell new members this focus before they come to the first meeting.
  
  Example: This support group is for persons with brain injuries to discuss their personal feelings and work toward greater productivity in the future.

- **Designate a contact person:** This person can talk to prospective group members (usually by phone - their contact number should be on a flyer or pamphlet) and determine if the group is a good match for a new member.

4) **Identify Type of Group – Open-Ended vs. On-Topic**

<table>
<thead>
<tr>
<th>Open Ended Meetings</th>
<th>On-Topic Preplanned More formal meetings</th>
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<tbody>
<tr>
<td>o Discussions are initiated by a facilitator and/or members with group participation at each meeting; discussions deal with current issues, problems, ideas, thoughts, emotions, etc.</td>
<td>o A speaker talks on a subject of interest and there is a discussion afterward.</td>
</tr>
<tr>
<td>o Needs a good facilitator.</td>
<td>o Topics are based on the predetermined needs of the group.</td>
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<tr>
<td></td>
<td>o Pertinent informational material is made available (flyers, informational packets).</td>
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<tr>
<td></td>
<td>o Requires preplanning, organization, and someone to organize paperwork, locate and communicate with speakers, etc.</td>
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<tr>
<td></td>
<td>o This is sometime called a “recovery group” vs. a “support group”.</td>
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Note that some groups will work best with a mix of both open-ended and on-topic sessions.
5) **Locate a Meeting Place**

Seek out no-rent or low-rent options:
- church fellowship hall
- recreation center
- multi-purpose room
- library conference room
- a mall community room
- university lounge
- school meeting room

**Do not overlook organizations** like Civitan Clubs, Kiwanis Clubs, Moose Lodges, Knights of Columbus, and other service organizations that often have available facilities.

**Try to avoid a member’s home as a meeting place** as it may cause problems relating to security and privacy.

**Considerations in choosing a meeting location:**
- Convenience to members who drive
- Convenience to public transportation
- Childcare needs of group members
- Adequate space for confidential discussion
- Accessibility for people with disabilities
- Suitability to needs of the group (e.g., room accommodates a circle of chairs; refreshments allowed)
- Safety issues (good lighting, on-site parking, ramps, and safe neighborhood)
- Availability during the regular meeting time as well as year-round availability
- Acoustics
- Level of distractions such as street noise, traffic, and other activities taking place at the same time (e.g., choir practice in a church)
- Comfort (e.g., temperature, seating, lighting)

**Choose hospitals or rehabilitation facilities if** your group wants to attract families of people in the hospital during their time of need and crisis.
- In this case, it may be recommended that the group have access to a professional in the field of brain injury since this group’s needs may extend beyond the scope of a typical support group and a brain injury specialist can usually identify other readily available resources.
- Keep in mind that this may not be desirable due to negative memories of time spent in hospitals and rehabilitation facilities.
6) Choose a Meeting Time

*Keep meeting time consistent.* This will help people with memory difficulties or very busy schedules attend meetings regularly. To determine a time to meet that will be convenient, consider the following:

- Child care needs.
- Respite care needs.
- Availability of transportation.
- Work schedules of group members and of the group facilitator.
- Traffic at that time of day.
- Availability of meeting place at that time.
- Distance to and from meeting place for most members.
Publicizing the Group

A simple publicity plan will help launch the group, laying the groundwork for a successful first meeting and a continuous community presence.

- Founding members should develop an announcement to be distributed, posted, emailed, and published in the local community.
- Announce the group at least thirty days prior to the first meeting.
- The announcement should include the support group title, the time and place where the meeting will be held, purpose of the meeting, and a contact person who is available to provide additional information.

You will find 2 sample meeting announcements following this section.

Consider potential dissemination sources

Call BIAV and ask them to include your announcement in the newsletter. (You may also be able to have the information passed along to people in the BIAV database in your area).

Call and send or deliver flyers for maximum impact. Places to distribute could include:

- Doctor’s offices, rehab facilities
- Home care agencies, outpatient clinics
- Social services offices
- Vocational rehabilitation agencies
- Civic organizations
- Therapy, counseling centers
- Domestic violence shelters
- Local VA hospitals

For broader outreach, post at places where everyone goes: grocery stores, churches, schools, and shopping centers.
Media Involvement

- **Feature Stories** - Sometimes television, radio, or newspapers will help out. Most of these media companies have “community activities” and “human interest” departments. Contact the person who usually covers the type of story you want. Convince this individual that there is a good story in your support group and encourage him/her to support publicity for the group. A feature story about an individual will often attract the media and can serve as a good lead-in to information about the support group.

  - **Before contacting the media** - Be sure you have all details of the group available and can answer questions and provide interesting facts. BIAV can help by providing fact sheets.

  - **Provide the name of an expert on brain injury to the media.** BIAV can help here too.

- **Free Listings** - Local newspapers will list your meetings in the calendar section.

- **Professional Organizations** - Some organizations with newsletters and calendars will include an announcement about a support group for free.

- **Other Media** - Don’t overlook local business, minority newspapers, and local cable programs.
THE RICHMOND SUPPORT GROUP
OF
THE BRAIN INJURY ASSOCIATION OF VIRGINIA

Announces

FACILITATED SUPPORT GROUPS FOR:

ADULTS LIVING WITH A BRAIN INJURY AND
FAMILY, FRIENDS AND OTHER CONCERNED PEOPLE IN THE LIVES
OF THOSE LIVING WITH A BRAIN INJURY

WHERE? CHILDREN’S HOSPITAL
2924 BROOK ROAD, RICHMOND, VA
* * MEETS IN THE AUDITORIUM * *
(Follow the posted signs)

WHEN? ON THE THIRD MONDAY OF EACH MONTH
6:15 to 7:45 p.m.

There is an opportunity to socialize and meet others at 6:15 p.m.
The group meetings begin at 6:30 p.m.

APRIL 2013

Mon., April 15th
Facilitated Support Group for people with brain injury, family members, friends &
others. What are your challenges? Your victories? Your strategies?
Come, share, learn

>> If those attending wish to, we will break up into two groups: one for people with brain
injury and a separate one for family and friends.

For more information contact Christine at BIAV:
(804) 355-5748 or email: info@biav.net
SAMPLE ANNOUNCEMENT 2

BRAIN INJURY SUPPORT GROUP

For people who have sustained brain injuries due to trauma, stroke, aneurysm, tumor, disease, or other neurological incidents

And

Family, friends, and other concerned people in the lives of those living with a brain injury.

- Discussion
- Socializing
- Support
- Information
- Friendship
- Encouragement

FIRST MEETING

Date: Wednesday, February 27, 2013

Time: 7:00 p.m. – 9:00 p.m.

Location: Hudson County Mall, Community Room
(Next to McDonald’s in the Food Court)

Register: No registration or fee required…no obligation…Just come!

For more information about the meeting, the Brain Injury Association of Virginia, and directions to the meeting, contact:

Dr. John Smith,
Neuropsychologist & Group Leader
Community Hospital (804) 555-1234
Planning and Holding the First Meeting

Here are a few things to remember when planning for the first meeting.

**Have an agenda.** Composing and using a written agenda can help you stay on topic. The first agenda should always include group introductions and a brief discussion of logistics such as meeting times, length, etc.

The first meeting should start and end on time and should be between 90 minutes and 2 hours long.

> Keep the first meeting simple, strong, friendly, and focused.

Members may feel guarded and apprehensive about sharing personal information at first. To ease transition, group founders should be prepared to initiate and facilitate discussion, and talk about themselves and their reasons for being a part of the support group. Encourage others to share their reasons for joining the group but allow attendees to participate at their own comfort level.

**First Meeting Details for Group Leaders**

- Post a sign at the entrance of the meeting facility to direct and welcome participants.
- Arrange seats for interaction (a circle or oval works well for discussion).
- Greet and give each person a name tag.
- Give each person a written agenda (optional depending on group).
- Circulate sign-in sheets for the names, addresses, phone numbers, e-mail addresses and other information from attendees. Provision of information is voluntary and all info remains confidential.
- Have handouts on local resources and information about brain injury available for perusal before the meeting.
- Develop welcome and opening remarks.
- Stress confidentiality of personal information shared.
- Review group etiquette for this meeting.
- Inform the group of the ending time.
- Have members introduce themselves; suggest 1 or 2 things they might share.
- Use a flipchart for discussion and notes regarding future needs and expectations.
• Discuss and plan with full participation:
  o Desired focus of the group.
  o How to meet unmet needs.
  o Date, location, and time of the next meeting.
  o Etiquette guidelines for ongoing meetings. (p. C 1)
  o Frequency of future meetings.
  o Who among the members are inclined and able to participate in leadership. (p. C 26)

• Encourage membership in the Brain Injury Association of Virginia.
• Allow for social time (refreshments optional).
• Formally close the meeting at the agreed-upon time.

Note: Adapted from How to organize a head injury support group. (1984). Brain Injury Association of Massachusetts.

**Remember:** People may be anxious to experience the benefits of interacting with others familiar with brain injury. Individuals who attend the support group need to leave feeling that they gained something or they may not come back. However, for the first meeting, this discussion may need to be limited as it can easily take away from the business agenda.

Discuss transportation concerns. Transportation issues specific to your group can be discussed at the first meeting. Keep in mind that many people who want to attend the brain injury support group do not drive, particularly at night, and public transportation may be limited. Ideas for solution to any transportation issues include:

• Carpooling - members can discuss this and plan for future meetings.
• Check with local civic organizations; they may be able to provide rides.
• High school groups (ex. the Key Club) may take on transportation coordination as a project.
• Support group leaders are discouraged from transporting group members to and from group meetings to minimize personal risk.

Check with other organizations to see about arranging group meetings on the same night. A school or similar facility may have rooms available so that several groups are meeting at the same time. Other groups meeting at the same facility may not have transportation problems and some members might provide rides.
Leadership and Facilitation

Effective leadership will strengthen the group a great deal. In some support groups, one person fulfills the roles of both coordinator and facilitator. In others, the jobs are held by two different individuals. Both arrangements can be functional. Both terms are used throughout this guide, with ‘leader” used as the more generic term.

By definition, the responsibilities of the coordinator and the facilitator are quite different:

<table>
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<tr>
<th>The coordinator</th>
<th>The facilitator</th>
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<td>guides the group as a whole, deals with the practical details of the group, and serves as a liaison to BIAV.</td>
<td>ensures that the group process meets the emotional needs of the members.</td>
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Leadership Tips for Support Group Coordinators and Facilitators

Keep meetings positive and encouraging:
The number one reason people give for not wanting to go a support group is the perception that it’s a bunch of people getting together to whine and complain. While members need to be able to bring up problems, you always need to bring the focus back to finding solutions. Don’t allow the meeting to degenerate into an anger or self-pity session. When a problem is presented, encourage other members to come up with positive ways to deal with it.

Be a better listener than you are a talker:
People need to be able to share their problems with someone who understands what they’re going through but they don’t need to hear all of your problems.

Develop your own personal support system:
Find one or two trusted friends with whom you are comfortable sharing your personal struggles. You need individuals in your life that will celebrate with you on good days and comfort you on bad days.

Connect with other support group leaders:
Whether you meet in person, talk on the phone, or communicate through email, it is helpful to develop relationships with other support group leaders. You can exchange meeting ideas, share strategies, troubleshoot problems, and encourage one another during those times when you wonder whether it’s all worth it.
Set limits and stick with them:
It is easy to have your life hijacked by a few group members who want your attention and will call at all hours. If this becomes an issue, decide which days and times are best for you to take calls and inform the people who call most often or announce it at the meeting that those are the only times you will be available to talk. Do not answer calls from members any other time. It's worth a small investment in an answering machine and/or caller-ID to protect your time and maintain your privacy.

Encourage members to use the buddy system:
Everyone needs someone to talk to, someone to commiserate with them. But you cannot be that person for every member of the group. Urge individuals to find someone in the group with whom they can exchange phone numbers and agree to be a mutual support system.

Be on the lookout for other potential leaders:
When you find a group member who exhibits leadership qualities, consider training him/her and keep that person involved by giving them specific tasks. Even if you have a co-leader, it's a good idea to have someone in training just in case. Sometimes both leaders are unable to attend and the backup has to jump in and lead the meeting.

Ask for help when you need it:
It's easy to fall into a pattern of doing everything yourself. Have a serious talk with the group and make sure they understand that the group depends on everyone's participation. This way no one is overwhelmed.
The Coordinator

Responsibilities/Duties:

- Serves as liaison to BIAV
- Ensures the group meets in accessible, appropriate meeting space
- Develops meeting times and schedules with group members
- Ensures that meetings are publicized
- Together with group members, plans and implements meeting agenda (e.g., inviting guest speakers, using the disclaimer appropriately, planning special programs, organizing activities, procuring videos, tapes, and hand-out materials)
- Ensures that follow-up is provided as needed (e.g., thank you notes, phone calls)
- Together with group facilitator and/or members, may open and facilitate group discussion, encourage participation, and monitor discussion
- Ensures new members are welcomed
- Arranges for refreshments
- Develops and implements a plan to ensure communication with group members between meetings as necessary (e.g., mail, email, phone tree)

The following tasks are easily delegated:

- Maintaining a group contact list
- Mailing or emailing meeting notices
- Greeting new members
- Arranging for and setting up refreshments
- Following up with new members
- Preparing the location for each meeting
- Cleaning up after the meeting

A strong support group coordinator should:

- Have a solid understanding of brain injury and its impact on individuals and families.
- Be able to communicate courteously, respectfully, and frankly one-on-one and in front of the group.
- Be able to manage the logistics of the support group.
- Have the ability to work independently to achieve goals.
- Be adept at identifying individual tasks and timelines and finding the right people to complete them.
- Be skilled at encouraging people and getting them excited about taking responsibility for their tasks.
Phone Skills for Coordinators:

As the support group coordinator, you may be the first point of contact by phone. Here are some tips for successful phone interactions:

- **Note the courage of the caller.** You may be the first person the caller has reached out to and asked for help. To support a caller who may be anxious, compliment the person on having called.

  - **Frequently use the caller’s name.** If the caller has given you a first name, jot it down and use it frequently during the telephone call to communicate a sense of caring.

- **Be an active listener.** Don’t interrupt with your story or advice.

- **Clarify the person’s problem or needs.** During the course of the conversation, clarify the caller’s issues and expectations. If your group is not likely to meet the caller’s expectations, let the person know and, if possible, refer him or her to a more appropriate resource.

- **Share some of your experience.** While sharing experiences is fundamental to support, during this initial contact, talk about your own brain injury or experience as it relates to the caller’s experience. Refrain from overwhelming callers with the burden of your issues as well as his/her own.

  - **Be clear about your limitations.** Present yourself as yourself - another person who lives or works with someone with brain injury - and focus on sharing what has worked for you. Refer callers to BIAV for information and referrals assistance.

- **Follow through on promises.** The credibility of your group is at stake. If you make any promises to call back or send literature, follow through as soon as possible. If you don’t have the time, ask someone else in the group to follow up.

  - **Be as accurate as possible.** As contact person, you need to explain the purpose of your group and what it does, and does not, offer. Callers will need factual information, such as the date, time, and meeting place of your group. Make sure they write the information down as you give it to them; if they have email, offer to send the information as well.

- **Try to offer “cautious optimism.”** Often a caller believes you and your group can “make it all better.” You can’t make their issues or concerns disappear, but you can offer something positive, such as saying, “Now you know that a support group exists and we are here for you.”

**The Facilitator**

The facilitator leads the group discussion/supportive session by:

- Helping participants stay focused on the present and on issues relating to brain injury.
- Ensuring that participants follow the group rules.
- Guiding individuals so that each participant has an opportunity to contribute.
- Finding a balance between letting individuals talk and involving the group in discussion.
- Skillfully prompting less vocal members to participate and limiting the conversations of dominant members.
- Guiding the direction of the discussion with suggestions, questions, and relevant feedback to keep the group progressing.

**It is NOT the facilitator's job to “fix” anyone.**

It is difficult to sit by and witness someone’s grief or pain, but it is in the witnessing that healing happens. The facilitator needs to learn to trust the support group process and avoid offering “fixes” or asking the group to fix an individual’s problem.

The facilitator will need support from someone outside of the group, an individual who can help the facilitator process his or her own feelings about what happened in the group. As facilitator, you cannot deal with your own issues in the group. This becomes too confusing to the group and may leave them feeling “leaderless.”

**If group members are leading a group, try having two facilitators alternate meetings, so that each has a chance to bring up personal issues.**

The group facilitator guides the group discussion, striving to make it productive for all the members. The facilitator is a helper, not a manager. The facilitator keeps the group in motion; initiating discussion, moving it along, and keeping the group on track; and removing blocks that inhibit participants from expressing themselves. The facilitator accomplishes this by:

- **Modeling the behaviors** he/she wants to elicit from the members such as empathy, emotional openness, encouragement, feedback, and acceptance.

- **Interpreting group interactions** in the context of the support group process. For example, when group members express similar feelings and experiences, the facilitator calls this to the group’s attention, offering a ‘reality check.’ He/she may help the group understand what these feelings mean and the importance of disclosure in the development of group cohesiveness.

- **Maintaining boundaries** or structure in the group.
Qualities of a Strong Group Facilitator

Various people may facilitate brain injury support groups. A person with a brain injury, a family member, a professional group therapist, or a rehabilitation practitioner can run the group. It is up to the group to decide whether the facilitator should be a person with a relevant professional background or a layperson. It is beneficial, however, if the facilitator has the following personal characteristics:

- Self confidence
- Sound judgment
- Maturity
- Low anxiety
- Ability to focus
- Perceptiveness
- Flexibility
- Sense of humor
- Empathy, compassion
- Concern for people
- Tolerance, patience
- Ability to interpret and articulate

The facilitator must also:

1) be able to connect with other people and maintain a **strong sense of self**, as he/she will be confronted with intense feelings, such as denial, hostility, and blame.

2) have a solid understanding of brain injury in order to facilitate honest interpersonal work.

**A strong sense of self** means the facilitator understands him/herself and his/her own feelings and is able to avoid transferring feelings to group members, taking things personally, or becoming involved in power struggles.
**Shared Leadership**

In small groups, it is quite possible that no one person appears to have all of the skills to lead or facilitate the group. For group coordinators, that problem can be overcome by taking an inventory of the skills in the group and delegating responsibilities to a number of people. In most cases, the ability is there and will emerge as each person takes on tasks. It may be a good idea to have people share tasks at first so they can work as a team.

Members involved in shared leadership will find themselves involved in determining the direction of the group. Members will develop a strong sense of ownership in the group when they help plan the discussion topics for each meeting. Sharing duties such as recruiting speakers, publicizing the group, or preparing handouts will distribute the workload so one person is not in charge.

**Shared facilitation works differently than shared coordination.** If there is no one with the desired facilitation skills, it may be necessary to look outside the group. However, some members may have many, but not all, of the skills to facilitate, or they may lack the confidence or experience to take on the responsibility by themselves. In that case, they may feel less intimidated and more comfortable facilitating if they can partner with someone and ‘tag team’.

**Good communication between the co-facilitators is vital before, during, and after the meetings.** Both facilitators can grow in the role if they take the time to discuss the group process with each other after the meetings.

**Tips to Increase Participation in Leadership Roles**

- To encourage a mutual exchange process, try arranging seats in a circle or around a table. When people are arranged in rows facing a leader, the group tends to focus on the leader.
- Adjust the seating arrangements to facilitate sharing while allowing room for people using wheelchairs or scooters.
- Integrate new group members by seating new members between older members for maximum sharing of ideas. Try to avoid clusters of old members seated together and ‘taking over’ the meeting.
- Brainstorm on activities, topics, and jobs to be done, and circulate a skills/resource sheet. Every member fills out a sheet with their name, skills description, type of personal contacts, and phone number (e.g., journalist in the family, aunt owns a bakery). This will provide a list of names, skills, and resources to match up to jobs.
- Build on already existing friendships by asking pairs or trios to take on projects together.
- Consistently and publicly acknowledge and express appreciation for work done by others.
- Nurture and grow volunteers by assigning small helper jobs and thanking them.
- Consider a responsibility sign-up sheet and include a “term length” so that people don’t get stuck with the same jobs permanently.

Information and Suggestions for New and Existing Support Groups
Support Group Etiquette

While a support group must be flexible to respond to the needs of individuals, it is wise to have some guidelines in place. For the group to function productively, participants will need to observe some basic rules of good group behavior.

Support group participants should decide these rules for themselves, as they will be more committed to abiding by them. Together, you should develop rules for your group regarding such things as a smoking policy, limitations on food and drinks, and behavior that may automatically exclude participation (e.g., intoxication).

IT MAY BE HELPFUL TO REVIEW THE RULES BEFORE EACH MEETING OR TO POST THE RULES WHERE ALL CAN SEE THEM.

Here are some simple suggestions for newly formed groups:

Example A:

Support Group Ground Rules
- Do not curse.
- Listen without interrupting.
- Maintain confidentiality! Do not share group content outside the meeting.
- Participate in the group discussion to the best of your ability.
- Accept one another and refrain from judgment or verbal attacks.

Example B:

As Support Group Participants, We Will…
- Respect everyone’s privacy; what is said in the group stays in the group.
- Avoid interrupting someone who is speaking.
- Refrain from having side conversations during the meeting.
- Talk about ourselves or our own situations, not others.
- Suggest and support, not judge, criticize, or ridicule.
- Listen to others and not dominate the conversation.
- Arrive on time. When we can’t help being late, we will not disrupt the meeting.
- Begin and end our meetings on time.
- Respect everyone’s personal space.
- Encourage people to speak up and express their feelings.
- Share in the responsibility for making the group work and for supporting one another.
- Encourage independence not dependence.
- Promote an atmosphere of trust and support.
- Strive to make new members feel welcome.
**Special Considerations for the Group**

**Ethical Issues**

Ethical dilemmas test the ability of the support group to function in a morally responsible way. It is necessary for the support group to have an ethical baseline in order to:

- Define its purpose.
- Set the parameters of its responsibility to members and participants.
- Identify the responsibilities of the individuals in the support group.
- Resolve conflicts.

The ethical baseline is the “moral compass” for the group, guiding individual participation and protecting the integrity of the group. For example, the support group may have to diffuse highly emotional situations, deal with a chronically disruptive member, address needs that go beyond the group’s capacity, and be consistently sensitive to members from a variety of cultural, racial, economic, and religious backgrounds.

The best strategy for addressing ethical issues in the brain injury support group is:

1) To be as prepared as possible in order to prevent and/or manage ethical dilemmas and
2) To have a simple, common-sense approach to problems when they arise.

The first step in preparing for ethical issues is establishing a relationship with BIAV. The national and state Brain Injury Association offices have staff experienced in dealing with difficult issues, legalities, liabilities, crises, etc., and should be used as resources to advise support groups regarding potential dilemmas and solutions. BIAV staff will assist a brain injury support group to maintain a sound structure and effectively respond to difficult issues.

**Ensuring that the ethical guidelines for the support group are clearly established and understood by all group members is an important preventative measure.**

The support group should decide and write down what behaviors are acceptable and what behaviors will not be tolerated. The support group should clearly define the consequences of unacceptable behavior. The limits of the support group’s responsibility to attendees should also be made clear. For instance, will the support group provide professional referrals to newcomers who request them? The state and/or national association have already addressed some of the questions that can come up at a support group, but many questions will require the individual support group to make a decision.
An example of a situation that tests a support group’s ability to function ethically is when a person comes to the group with a problem that surpasses the group’s capabilities. It is irresponsible for a group to allow a person in crisis - be it situational or emotional - to participate and leave the support group without resolution. It is also irresponsible for the group to do more than the members are qualified to do.

The support group can be an appropriate place for the expression of pain, anger and conflict; however, the support group may simply not be able to provide an immediate or complete solution to a particularly complex problem.

The support group should strive to understand, validate, and support individuals in extreme need; however, a group resource person may need to meet individually with a person in great need (during or after the meeting depending on the immediacy of the problem). This group member should take reasonable steps to ensure that the person is able to pursue the necessary and available resources (e.g., provide transportation, make initial phone calls, etc). In a responsible support group, at least a couple of key group members need to have a working knowledge of community resources such as mental health centers, crisis telephone lines, emergency shelters, and nearby medical facilities.

### Diversity within the Group

If there is one thing that many individuals with brain injury and family members have in common, it is the belief that, “Other people do not understand.” As true as that is, it is equally true that people with brain injury do not automatically understand each other. While there is an incredibly strong common bond, there are also great differences, due to varied circumstances and roles. A spouse and a parent might both be caregivers, but their circumstances, issues, and concerns may be very different. A young parent caring for a child faces an entirely different set of issues than an elderly parent trying to care for an adult with brain injury.

A support group that tries to handle all the issues facing everyone in the group is bound for failure. Ideally, there should be support groups for adults with brain injury, children, parents, spouses, and siblings; unfortunately that is not always practical. Instead, it is important for the members of the support group to:

1) understand where everyone in the group is coming from and
2) when possible, provide a forum for addressing specialized issues.

This might be made possible by having all caregivers participate in the same support group, but also by arranging a time for the spouses to get together on their own.

### Differences related to background and circumstances

One of the things that make the American culture so rich is the diverse and varied races, religions, national origins, and a host of other factors. In the support group, these factors make every person’s situation different. Rather than presenting a problem, these differences should be viewed as enhancing the group by providing a rich diversity benefiting everyone.
Differences in ethnic and/or religious background
A person’s ethnicity and/or their religious background can affect how they seek help and assistance. Some people may avoid the support group, believing that the family alone should deal with their problems. While there is nothing wrong with this belief, the individual with brain injury and their family members could benefit from the support group if they feel comfortable enough to try it.

In an area where minority populations might be small, it is very possible that no one from a particular minority group may be involved in the local support group. The first African-American, Hispanic, Asian, or Native American member of the group might feel that he/she does not belong. The challenge to the members of the support group is to make that new person feel welcome and to accept his/her concerns and issues.

TIP: When planning publicity strategies, make a point to reach out to diverse populations in the area to ensure that the group is well represented and unbiased in its attempt to include people from many different groups and backgrounds.

As difficult as it might be for an individual with brain injury to fit into a community, think about how much more difficult it is to be a different color or religion than most of the other people in the community. If an individual is not welcomed by the only people who might truly understand what he/she is feeling, where else can that person turn?

Differences in level of disability
The same problem might exist regarding different types and levels of disability. An individual with brain injury who is deaf or blind will face very different barriers than other people in the group. However, these individuals will still need the help of the support group.

Other issues to consider
What if someone wants to participate in the support group who cannot speak English, requires a sign language interpreter, and/or needs materials in Braille? These are difficult issues and, unfortunately, may sometime be beyond the ability of the group to deal with internally. That does not mean problems cannot be resolved.

Translation services:
If someone does not speak English, there are several options:

- Perhaps the participant has a family member or friend who does speak English and who can attend the meetings.
- Check with the foreign language department of local colleges. Many colleges have faculty members willing to help or proficient students who are either willing to volunteer or able to use the time an effort as part of a class assignment.
- Foreign language clubs at a local high school may help as well.
- Advertise in the local newspaper to see if someone in the community is proficient in the language and willing to volunteer their time.
- See if there is a community center related to the nationality of the new group participant (e.g., Korean Citizen’s Center).

Unless the language is very exotic, there are normally people in every community who can lend assistance.
Sign language interpreters:
Qualified sign language interpreters can be much more difficult to find.
- In some states and localities, government agencies may be able, or even required, to provide these types of services. If these agencies cannot help, ask for recommendations. They may know of training programs for interpreters.
- Check with local schools and universities that can make referrals to the people that they use. Check with the sign language curriculum instructors and ask if they have faculty members or proficient students who are either willing to volunteer or able to use the time an effort as part of a class assignment.
- Again, it may be helpful to advertise in the local newspaper.

Braille materials:
While the support group may not be able to provide the material at the last minute, with enough advance notice, the support group should be able to obtain Braille materials in time for future meetings. It may not be as difficult as you might imagine.
- State, federal, and local agencies may have the ability to provide materials in Braille and might be able to help, particularly, the state agency for the blind and visually impaired.
- Local courts, as well as banks or insurance companies, may also have Braille ability.

An issue that frequently comes up regarding people needing special accommodations is the question of who will pay for them. Hopefully, the group will be able to find volunteers. If this is not possible, the support group should see if funds are available through various social service agencies. Check with BIAV and see if they can locate the accommodations and the resources to pay for them.

Unfortunately, the support group may not be able to find the services needed or find someone willing to volunteer the time. This will be one of the toughest issues a disability group can face because it may mean having to tell the individual that the group simply cannot provide those unique accommodations. The decision is not only a very difficult one; it may also have some legal ramifications under the Americans with Disabilities Act. The law requires that “reasonable” accommodations be provided. If the group has made the effort to find the services and failed or does not have the resources in the group to pay for them, then the group is not required to provide them. If the group reaches this point, contact BIAV to make sure that every possible solution has been attempted and document your efforts.

There is no hard and fast rule for dealing with the challenges of diversity. The best advice is to be creative and ask everyone in the community who may be of help.

*Remember, the number one reason people do not offer help is that they are not asked.*
The Supportive Session

Content

The content of the support group session is up to the members to decide, with input and assistance from the facilitator. As a basic rule of thumb, group members should keep in mind that they will reap more benefits by keeping the group’s focus current. Events of the past, including childhood, the injury, rehabilitation, and other past experiences should be discussed as they relate to the present.

Some brain injury support group members tend to re-tell their story at every meeting, perhaps as an attempt to make sense of the trauma and impose some order or control in their lives. This makes the individual and the group stagnant. Anxiety about the future, short-and-long-term goals, and upcoming issues should be addressed in terms of the present. It is more empowering for a group member to talk about the positive steps he or she can take toward the immediate future.

To clarify, group members will want and need to talk about their injuries and their fear about the future and that is okay. In order for empowerment and progress to occur in individuals and the group, the facilitator and members need to connect the events of the past and possibilities of the future to what matters the most - the ability to seize today.

Often, someone will want to lead the discussion in a direction that meets personal needs. This may take the group away from its agenda, the topic, or a meaningful discussion in progress, requiring the facilitator to re-direct the conversation. A skilled facilitator might first consider whether the new discussion is of interest to the other members of the group, and if so, let the conversation flow in that direction. Many of the best support group sessions occur spontaneously after one person opens a new door.

Don’t Forget to Include Laughter

The support group should not always be dark and depressing. People do have successes to celebrate and jokes to tell. It can be therapeutic to learn to laugh at oneself.
Group Facilitating Techniques

There are many good textbooks on using general counseling techniques to lead groups. What follows is a brief summary of some of these techniques and some examples that frequently occur in a brain injury support group. A facilitator should try role playing these techniques with a co-facilitator.

1) Restatement of content

The facilitator attempts to convey understanding either by simple repetition or by rephrasing an individual’s statement. While this seems simplistic, the individual will feel heard and will generally continue to delve deeper into his or her feelings.

Susan: I feel so helpless. None of the doctors seem to think this should still bother me.

Facilitator: So Susan, the doctors’ lack of understanding just adds to the despair you’ve experienced because of the continued problems since your injury.

Susan: Yes! It makes me feel even worse; like I’m making it all up and that these headaches are not even real!

2) Questioning

This technique can often be overused, probably because people are uncomfortable with silence. Questioning is best used to:
(a) Get specific information and
(b) Direct the individual’s conversation to more fruitful channels.

Frequently in group discussion, another individual may interrupt someone’s story with a question that diverts the speaker from the real issues. It is the facilitator who must get the speaker back on track. Useful questions include:
• “How do you feel about that now?”
• “What about the diagnosis scares you?”
• “What might you ask friends or neighbors to help with, so you have a little free time to care for yourself?”
• “What do you need to know about speech therapy to choose a therapist?”
3) **Maintaining Focus**

A listener may interrupt a narrative with a question like “I lived in Santa Fe too - did you like it there?” or “I was at the rehab place too - do you know Joe and Mary?” These questions distract and divert the conversation.

The facilitator can help the speaker get back on track by repeating what they were talking about: “You were saying that you felt scared to drive again?”

To keep the group focused, the facilitator might remind the participants that they can talk after the group: “Bob, let’s let Sara talk about her accident now; you guys can talk about Santa Fe at social time.”

It is important to remember that for some individuals, the support group may be one of the few times to socialize. These members may need help staying focused.

4) **Reflection of Feeling**

This is an attempt by the facilitator to understand a member’s point of view and to communicate that understanding.

In the previous example of Susan, the facilitator might reflect content: **“In other words, it’s the doctor saying you should be over the injury now that upsets you?”**

The facilitator could also reflect feeling: **“If I understand correctly, you feel like the doctors think you’re pretending about these very real problems you still have.”**

Or the facilitator could reflect the core meaning: **“So what you’ve said is that the doctors act like there are no problems left, yet you know that there are.”**

Each of these statements helps the speaker feel that the facilitator understands and will encourage him or her to keep speaking.
5) **Encouragement**

Encouragement is designed to counter feelings of inadequacy or to prompt action. It may help to bolster the individual’s ego strength. Examples of encouragement are:

- “You’re doing fine.”
- “You can do that.”
- “You’re okay.”

This provides honest, positive feedback to the speaker. For those individuals who have difficulty speaking or finding the correct words, or for those people who cry and seem to be embarrassed by the display of emotion, encouragement helps them continue.

These are merely a few of the basic counseling techniques that can help the facilitator encourage individuals to clarify and work on their issues. In a group setting, the trick is to allow individuals some time to talk and to involve others in the group. Sometimes other group participants need to talk or just want to change the subject but feel that it would be impolite to interrupt. Unfortunately, the support group may be the only opportunity for emotional support an individual will get, but it is not a therapy session for one person and the facilitator may have to stop one person from talking too much at times.

### Techniques to Keep the Group Moving

1) **Acceptance**

*This is crucial to the support process.* Verbal (e.g., “Mmm-hmmm,” “I see,” and “Yes”) and nonverbal behaviors (e.g., turning towards the speaker, smiling, nodding, showing appropriate facial response) help the speaker to feel understood and show the group that the speaker is being taken seriously.

These verbal and nonverbal cues are effective for keeping the group moving, but there are also other benefits of these behaviors. By using these verbal and non-verbal acceptance behaviors, the facilitator models good and polite behavior. Modeling can be very important to those individuals with brain injuries who need to learn more appropriate group behaviors. It is helpful for family members who usually act as caregivers to see their spouses and children treated like adults as well.

Acceptance is important to people with brain injuries. Some of them may have been hearing from their doctors that they really do not or should not have a problem. Family members may feel overwhelmed and seeing nodding heads may encourage them to express their feelings.

Acceptance is a key to healing - seeing it mirrored by others in the support group will help individuals move towards this important goal.
2) **Clarification**

To help clarify a statement made by a speaker, the facilitator should organize the idea, feeling, or attitude in a more cohesive and understandable form for both the speaker and the group. This technique may be very important for an individual with a brain injury who is having a hard time speaking or organizing thoughts. Should the facilitator err in his/her clarification, the speaker can take the opportunity to restate the issue.

An example of clarification:

**Mary:** “The doctor just left me sitting there and talked to my parents as if I wasn’t even in the room, telling them there was no more room for growth. I was so upset. It was as if I wasn’t even alive. They all think I’m a baby still.”

**Facilitator:** “You were angry at the doctor for talking over you because it’s your life, your injury, and they aren’t letting you take responsibility for yourself?”

**Mary:** “Yes! And I’m thirty years old! How can I get better if I’m not allowed to participate?”

The facilitator’s comment helped Mary and the group to focus on an important issue for individuals with brain injury. Facilitators must always be looking for ways to keep the process moving forward, using comments or leads that are open-ended and allow the conversation to deepen and not come to a premature halt.

3) **General leads**

These are questions used to encourage members to continue talking or to elaborate on a point they are discussing. A few good leads are:

- “Tell me more.”
- “How does that make you feel?”
- “Would you explain that further?”

Closed questions, those which can be answered with a yes or no (e.g., “Did you like that?” or “Did you go to that school?”), might not encourage someone to keep speaking. In the previous example, the facilitator could use a question to get other members involved:

- “Does anyone have any suggestions for how Mary could handle this situation?”
- “How would your parents like to see the situation handled?”
- “How do others feel about this situation?”

By phrasing the question carefully, you can move forward. If you were to ask, “Has this happened to anyone else?” you might get stuck in the past as people tell their ‘war stories’.

*Remember,* you are trying to keep the group focused on solutions to problems. While it is important to express one’s feelings about problems, it is not good to get stuck in the storytelling.
4) Information giving

This is an important technique in a brain injury support group and one of the critical reasons that the facilitator needs to have a strong understanding of brain injury. For the individual who seems frustrated with short-term memory problems, hearing that this is a common result of brain injury will alleviate a lot of stress. For parents who do not understand why their once reserved son is suddenly acting in a sexually inappropriate manner, hearing that previously learned inhibitions may no longer be present may help them deal with the situation instead of being frustrated by it. The idea is not to give medical advice without the appropriate medical background but to provide sources and commonalities that will encourage the member to move forward.

5) Advice giving

Often the request for advice is more a need for clarification or release from confusion. When asked for advice by a group member, the facilitator might respond by saying,

“What have you thought about doing?” or “How have others handled this situation?”

People with brain injuries and their families get lots of “advice,” often unsolicited. Providing examples of what has worked for others allows the individuals to make choices and take responsibility for their needs.

**Parent:** “I am feeling guilty about leaving my daughter to go out to a movie one night a month. What should I do?”

**Facilitator:** “How do other parents deal with this?”

**Another parent:** “We have an aunt come and sit with our daughter, or my neighbor lets our daughter come ‘help’ babysit for an evening.”

This works better than, “You should just get somebody - you have to get out!” or other similar responses that do not allow the first speaker to make choices. Giving advice can backfire if the individual follows the advice and it does not work or if he/she does not follow it and feels embarrassed and unable to return to the group.
6) Silence

Staying quiet is one of the most important and most difficult skills for a facilitator to learn! The facilitator may feel that he/she is not doing a good job if no one is talking. In our culture, silence can be uncomfortable but instead of jumping right in, the facilitator should try silently counting to ten. Usually before you get to ten, someone will have responded.

Here are some reasons that silence occurs, and suggestions for moving through it:

- Some people feel afraid of what others will think so no one says anything. Beginning with an icebreaker or suggesting a non-threatening topic to the group that may get things moving. It is good to come to each group prepared to introduce a topic in case a need arises. As in normal conversation, the subject may change. This is fine, as long as the group continues to move forward.

- Oftentimes there will be a silent pause because the group is thinking over something that was just expressed. Do not interrupt. Let the group work through their thoughts.

- Silence can occur after the speaker has finished his/her thoughts and does not know what to say next. The facilitator may break the silence or stay quiet until someone else picks up the discussion. Remember, in normal conversations, there are pauses.

- There may be an extended pause after remarks have been made and a topic suggested. The group may not like the topic or may not have anything to say. The facilitator can say something like, “It’s rather hard to get going today.”

- There can also be silence because painful emotions are being expressed and no one knows what to say. The facilitator can help by saying, “Sometimes feelings are hard to put into words, but perhaps expressing them is more important than choosing the exact words.”

- Silence can occur when an individual needs support or encouragement. Try saying, “Tell me more” or “I see.”

- When individuals are silent because something very sad or emotional has been said, it is important for the facilitator to exhibit quiet acceptance.

7) Universalizing

In this process, the facilitator tries to help each member become aware that his/her feelings and concerns are similar to those of other group members. The facilitator does this by intervening after an individual has talked. For example:

**John:** “Since my accident I don’t seem to want to go out to do things with my friends. It’s like I can’t fit in anymore.”

**Facilitator:** “John seems to feel like the accident has made him different. Do others feel that way? Or have a hard time with their friends?”
8) Linking

Like universalizing, the facilitator should be able to provide a linking mechanism between the feelings and thoughts of all members and to bring in other members who might not be talking. This will help build cohesion in the group. Example:

**Facilitator:** “I saw a lot of nodding heads when Larry was talking about having to start over. We have some older individuals in our group tonight. What has it been like for you, starting over at this stage in your lives?”

9) Blocking Inappropriate Behavior

The facilitator also plays the role of gatekeeper. He/she must block inappropriate group behaviors. One of the best ways to do this is to say: “I feel (state feeling) because (state behavior).” For example, “*I feel upset because you continually interrupt to tell people what to do.*”

This manual cannot tell you how to handle every tough situation that comes up. People may come to the group intoxicated, or make unwanted sexual comments, or create any of a thousand difficult situations. The facilitator can start by **trusting** his/her intuition and **addressing** as much as possible in the group. Taking individuals aside or out of the group can encourage the behavior; often the added attention can be empowering to the troublemaker.

If you are not a professional, utilize the support of a professional to discuss how to proceed. BIAV may be able to help. University counseling programs, psychologists, or church counselors may also be of some help. Additionally, admitting to the group that you are at a loss for how to handle a situation can be an opportunity for the group to grow as they come up with possible solutions.
Handling Conflicts

Sometimes, even the most prepared support group members and the most skilled facilitator can be caught off guard by challenging conflicts within the group. Potential problems can occur when individuals dominate the group, have explosive emotional episodes, confront other members personally, strike out at the leader, demand more than the group can offer, or hold the group accountable for their own personal circumstances.

- The facilitator should try to understand what the “challenger” is saying. Validating, supporting, or at least reflecting what a person is saying should immediately diffuse some of the intensity of emotions. The facilitator might say:
  
  “I hear you saying that you felt put down - is that right?”
  Or
  “I can see that you are genuinely upset about something that has happened.”

- The facilitator can provide feedback to the “challenger” through by engaging the group, taking whatever amount of responsibility is appropriate. An example might be:
  “I wonder if others are feeling confused by what just happened?”
  Or
  “What do other group members think we should be focusing on right now?”

- The facilitator, the person being confronted, or other group members should attempt to respond to the challenge. This does not necessarily mean that immediate action can be taken but some plan or progress should emerge. Taking the lead, someone might say:

  “Since we have decided to talk more about the upcoming transitions, let’s start with John’s departure next month.”

  “Some of us are feeling angry at the new facilitator, so let’s figure out how to avoid this conflict next time.”

  “As a group, I think we need to make more of an effort to listen to each other without interrupting.”

Do not forget to consider the obvious when attempting to resolve challenges or conflicts in the support group meeting. If you recognize that the reasons for some behaviors may be due to environmental or situational factors, many conflicts can be easily remedied. For example, if the meetings are loud with many people talking at once, someone may have trouble understanding what is being said. If other people are more vocal and dominate the conversation, someone may not have the opportunity to express something that is very important to him/her. An outburst may be a way of expressing this frustration. An interruption may also occur when someone feels the need to express a point before he/she forgets.
The facilitator should try to address disruptive behavior within the group context. Often conflicts can be resolved through open, honest group discussion and the influence of fellow members. After the meeting concludes, the facilitator may want to follow-up individually with the disruptive member. For example, if someone makes sexually inappropriate remarks or racial comments, the facilitator may want to sit down with the person privately, investigate the cause of the problem, and help the person resolve the behavior so that group participation can continue.

**Guidelines for Handling Difficult People in Support Groups**

People who exhibit challenging behaviors can cause issues for any group. Some suggestions for dealing with these behaviors:

- Recognize that behavior is goal-oriented.
- Reject the behavior but not the person.
- Recognize the problem may be both an individual and a group problem.
- Help the person find an appropriate way to participate.
- Work with the person outside the group to resolve problems.
- Help participants develop group-recognized operating procedures.
- Recognize that conflict can be constructive as well as destructive.
- Help the group develop procedures for solving the problem.
- Assess your own behavior in reaction to the behavior of the difficult person.
- Remember that prevention is the best insurance policy.

Encouraging Expected Behavior

If a particular member’s behavior is regularly disrupting the group, try “The Four E’s of Responding to Negative Behavior.”

The Four E’s of Responding to Negative Behavior
By Mike Martelli, Ph.D.

Event: When you (kick the desk in front of you, tap your pencil, talk out loud…)
Effect: It (distracts the group, violates the rules, interferes with someone else’s sharing time…)
Emotion: And it makes me feel (frustrated, confused, angry…) (share label for feelings but don’t show rejection).
Expectation: I like it better when you (ask to be excused, wait for your turn, sit quietly and listen…) (emphasize alternative, positive behavior).

If the four E’s are not sufficient after several efforts, consider the fifth E:

Or Else: If you continue to…(curse and interrupt) instead of …(a warning) …you’ll be asked to (leave the room at once).

The “Or Else” contingency needs to be:
• Fair
• Reasonable
• Proportional
• Firm
• Enforceable
• Related to the behavior
Suicide Threats/Concerns/Ideation

Develop an action plan for dealing with a distressing situation or crisis before it happens. Have it available and follow it. If there is a separate person who acts as a facilitator, a general game plan should be discussed in advance determining who might do what, should the need arise.

Keep a list of phone numbers for appropriate resources such as: helplines/hotlines, hospital emergency room, psychiatric emergency services, screening centers, local crisis counselors, ambulance, mental health center, and police.

Suicide Prevention Hotline: 1-800-273-TALK (8255). This hotline is open 24/7 and manned by trained counselors and is automatically linked to a crisis center close to where the person calls from.

Educational Resource: Refer to www.suicidology.org, specifically the tabs “How you can help” and “Thinking about Suicide?”

Some helpful guidelines are:
- Always take suicide threats seriously.
- Remain calm.
- Address directly - Either during or after the group (depending upon the immediacy of the threat), the facilitator or a prepared, skilled group member can meet with the individual in crisis.
- Listen! Empathetic listening is key. Venting emotions can help diffuse the situation. (Empathy means expressing understanding and concern by reflecting back the person’s feelings. For example, after listening to the individual in crisis, the helper may express empathy by saying, “I hear your disappointment and I know how overwhelming it feels to lose someone close to you.”)

The person who handles a suicide threat should always ensure that the suicidal person receives appropriate help outside the support group. This may mean taking the person to a mental health professional or hospital, contacting a family member to assist the person in crisis and waiting with the individual for the family member to arrive.

Do not underestimate the toll this experience may take on you and the group. Include the group in discussions regarding feelings of helplessness and despair allowing you to all work through this emotional experience together.

TIP: In the local telephone book in the ‘Blue Pages” section, you will find a crisis phone number for Mental Health Services. Look up the number for the location where your group meets and keep the number in an easy to find location.
Running the Meetings

The following is an outline of how a meeting might be conducted with time allotted for each phase of the meeting. This is just one example and can easily be changed to suit the specific needs of your group.

<table>
<thead>
<tr>
<th>A Sample Meeting Format</th>
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</thead>
<tbody>
<tr>
<td><strong>Opening and Introductions</strong></td>
</tr>
<tr>
<td>(5-15 minutes)</td>
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</table>

Unless everyone knows each other, a brief introductory period is helpful. This is the time newcomers are introduced and can speak briefly about themselves to the group. A long talk where each member tells “his or her story” should be avoided. It can lead to a long discussion of injuries and medical histories rather than focusing on the present.

<table>
<thead>
<tr>
<th>Old and New Business</th>
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</thead>
<tbody>
<tr>
<td>(10 minutes)</td>
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</tbody>
</table>

A small amount of time can be spent on housekeeping items, such as upcoming holiday events, a letter from a former member, an update on the new meeting space, etc. This is brief information-sharing time, reserved for the leader to make important announcements to the group. An alternative would be a facilitated, limited time slot for information sharing among members. Subjects that require group discussion, such as rotation of jobs/offices, should be reserved for a separate time.

<table>
<thead>
<tr>
<th>Support Group Session</th>
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<tbody>
<tr>
<td>(50-60 minutes)</td>
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Most of the time the support group spends together should be reserved for facilitated supportive exchange. If the group includes a significant number of individuals with brain injury and a number of family members, it is an option for the groups to divide for separate meetings. The facilitator formally closes the meeting each time, perhaps summarizing the group’s discussion.

<table>
<thead>
<tr>
<th>Social Time</th>
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</thead>
<tbody>
<tr>
<td>(15-30 minutes)</td>
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Most groups disband slowly as people chat with one another before leaving. The group may want to offer a short reception period after the meeting for people who want to talk informally and for new people who want to get to know others. A designated volunteer should stay until the end to ensure that everyone leaves safely and that any clean up and security issues are handled.
Group Discussion Ideas

The support group topics should be decided by group consensus. The following list of topics is intended for a discussion led by the facilitator or an expert on the topic.

Possible Discussion Topics for Persons with Brain Injuries

- Making new friends
- Dealing with anger
- Learning to handle not always being in control
- Maintaining independence
- Asking for and accepting help
- Challenges related to brain injury that I have faced and overcome
- Challenges related to brain injury that I have had difficulty handling
- Injury acceptance
- How brain injury affects travel and vacation
- Helpful strategies
- Dealing with an “invisible disability”
- Learning to communicate with my doctor about my brain injury
- Deciding whether or not to disclose a brain injury at work
- Asking for reasonable accommodations at work
- Dealing with fatigue
- Handling the reactions of family and friends
- Maintaining relationships with caregivers when receiving physical care
- How brain injury can affect the role of parent
- How brain injury can affect family communication
- Communicating feelings and needs
- Helping family and friends to better understand my brain injury
- Ways a case manager can help

Possible Discussion Topics for Caregivers

- Understanding changes in behavior
- Feelings of social isolation
- How brain injury affects relationships and marriage
- No one understands!
- Talking to children about brain injury
- Changes in daily routines since the brain injury
- Accepting the way things are
- Stress management
- Anxiety and sleep problems
- Energy boosting strategies
- Time management
- Staying organized
- How to fight fair
- Wrestling with guilt
- Overprotective tendencies
- How and when to let go
- Sleep problems
- Dealing with anxiety
- Signs of depression
- Loneliness
- Planning for the future
- Estate planning

Ice Breakers

Ice breakers can help a group discussion get started quickly and enthusiastically. Here are a few suggestions:

Icebreaker 1 (for new groups)

The leader passes a roll of toilet paper to the person closest to him or her and says, "Take as much as you think you need and pass the TP to the next person". The leader does not offer any more information.

Once the TP has gone around the room, the leader says to the group, "For every square that you tore off, tell the group something about yourself". This will make people laugh and the one with only one square will usually feel relieved!

Icebreaker 2 (focused conversation icebreaker for a new group)

Leader: “Please state your name and the number one reason you came here today.”

The leader goes around the room, getting a response from each person. Afterward, he or she chooses from the list of the following questions, allowing members to answer as they will.

1. What do you remember from these responses?
2. What words or phrases stood out for you?
3. Were there any surprises?
4. What did you hear that intrigued you or made you want to find out more?
5. What words or images would you use to characterize this group?
6. What connects us and draws us together as a group?
7. What strengths do we have that will assist us in our task?
8. How can we use them to be as effective as possible?

This conversation takes the group from basic information about themselves through impressions and some interpretation about why they gather together.
Icebreaker 3

The leader reads a quotation that may be suited to the group such as, “Life is the art of drawing without an eraser,” by John W. Gardner. The leader then goes around the room and lets each person say what that quote means to them. Notice how many points of view come from the same quote and see how we learn from each other.

Icebreaker 4

The group forms a circle. One person starts and looks to the person on his or her right and states one thing they have in common with that person. The person then names one characteristic that makes him or her unique (e.g., “I collect frog statues.” “I like to draw.”). At the end, the leader acknowledges that everyone has things in common as well as unique qualities to bring to the group.

Icebreaker 5

The leader brings in a paper cup. He/she holds it up and asks, “What is this?” The group answers, “It is a cup.”

The leader asks, “What is it used for?” The group responds, “To hold liquid or drinks.”

The leader asks everyone if they agree and then uses the cup to scoop something (candy or chips) and says, “Now it’s a scoop.” Then the leader pulls out a cup with a plant in it and says, “Now it’s a planter.” The leader ends by saying that people just generalize that cups are for drinking but they are for many things.

The leader can then follow up the demonstration with these questions:

- What generalizations has the group encountered? Ask about generalizations relating to their injury experience.
- What generalizations have people made about you?
- How does that make you feel?
- How can you help people better understand brain injury?


Icebreaker 6

Some groups have an outline for people to follow when they first speak. If the group is in a circle, members speak in a round robin (speak in turn of seating order).

Here is a sample outline:

- State your first name and tell us what brought you to the group.
- On a scale of 1-10 rate your week.
- Tell us about one good thing that happened over the past week (sets optimistic tone).
- How you are feeling right now?
- Tell us one positive thing you would like to do over the next week.

Guest Speakers

Where to Find Guest Speakers

- BIAV may be able to provide names of individuals who can speak on specific topics you have in mind.
- Tap into connections within your own support group. Members may know of an interesting speaker to recommend.
- Local social service and government agencies and hospitals may have lists of speakers.
- Local colleges and universities may have speakers who can present on topics related to your group’s interest. (For example, contact the psychology department for speakers to address stress.)
- Contact government agencies such as Social Security Administration or the Department of Aging and Rehabilitative Services.
- Lawyers specializing in discrimination law, financial planning, insurance, and/or disability law are another source of speakers.
- Contact professional associations (psychologists, social workers, nurses, doctors, speech pathologists, physical and occupational therapists) for local speakers on subjects such as medications or choosing a good therapist/doctor.
- Alternative health providers can provide information on herbal medicine, massage, meditation, yoga, or guided imagery. Be careful not to allow practitioner demonstrations due to safety reasons.
- Local pharmacists are a good source of information on drug interactions and taking medicines wisely.
- Invite representatives from another brain injury support group to talk about their group’s best meetings, discussions, speakers, and other successful activities.
- Consider using a pre-recorded or “canned” speaker (tape of a radio interview show, PowerPoint presentation, conference presentation, portion of a TV program, etc.) that is relevant to the discussion.

Types of Guest Speakers

Some examples of “experts” that you might ask to speak at your meetings include:

- Neurologists
- Neuropsychologists
- Psychologists
- Physiatrists
- Nurses
- Physical Therapists
- Occupational Therapists
- Speech Therapists
- Licensed Clinical Social Workers
- Recreational Therapists
- Music Therapists
- Exercise Therapists
- Vocational Rehabilitation Specialist
- BIAV Staff
- Attorneys
- Family Counselors, Sex Therapists
- Social Security Representatives
- Authors
**Guest Speaker Topic Ideas**

- What vocational services, recreational programs, and/or housing options are available in the community? (state Department of Aging and Rehabilitative Services)
- What does the state and/or national brain injury association do for me? (BIAV staff)
- What about driving? (state department of motor vehicles, representative of rehabilitation program that teaches driving courses)
- Legal issues such as trusts, wills, and power of attorney (attorney)
- Substance abuse issues (substance abuse counselor)
- Understanding pharmacological issues (neuropsychiatrist)
- Sexuality (sex therapist, family counselor, physiatrist)

**Preparing For and Hosting Guest Speakers**

If a support group decides to have a guest speaker, members will need to prepare and follow some simple, common courtesy procedures. Listed below are some useful suggestions:

- Appoint one person in charge of recruiting speakers. Ideally, this person should be someone who personally knows potential speakers. (As with other group responsibilities, this task can rotate among different members of the group.)

- Contact the potential speaker as far in advance of the meeting as possible. This will not only allow the speaker to prepare his/her presentation, but will also give the support group time to promote the program.

- Potential speakers not familiar with the group should be contacted first by mail, then via telephone. The initial letter should include information about the group as well as an invitation to speak and should be followed with a telephone call for further discussion and confirmation. If the group chooses to contact the speaker by telephone first and the speaker agrees to participate, a follow-up letter should be sent providing all the details described below.

- The follow-up/confirmation letter should include the time, date, and location of the meetings, along with specific directions once inside the building. In the letter, provide a brief overview of the group, the expected size and makeup of the audience, what information the group expects to receive, the amount of time allocated for the presentation, and any specific issues that may arise during the support group meeting. For example, the reason for inviting a speaker on social security may be because group members have had problems getting approved for social security. You should also attempt to give the speaker some idea about the level of audience expertise. This will help the speaker determine how technical the presentation should be.
• In addition to providing the speaker with the meeting time, let him/her know the full agenda of the support group meeting and the time at which the presentation is scheduled. The support group may encourage the speaker to attend the entire meeting in order to become acquainted with the support group.

• For introduction purposes, be sure to obtain the full name and title of the speaker. One of the best ways to do this is to ask for a short biographical sketch well before the presentation.

  • There are many excellent speakers who are willing to provide their time free of charge. It is important to discuss an honorarium with the speaker ahead of time and whether or not the group has the funds to pay an honorarium.

  • If there will be more than one speaker at the support group meeting, make certain that all speakers are aware that more than one person will be speaking. Provide each speaker with relevant information about the other speakers so that they may take the time to become familiar with each other. If they will be talking about related issues, suggest that they contact one another to coordinate their presentations.

  • Establish whether the speaker will need any audio-visual equipment and if so, whether he or she will provide it or if the support group can. If the group needs to obtain the equipment, the facility hosting the meeting may be of help.

  • While all the details should be ironed out several weeks before the meeting, the designated group member should get in touch with the speaker again a few days before the event. This is not only a courtesy, but also a subtle way to ensure that the speaker has not forgotten about his/her commitment.

**Support Group Meeting Disclaimer**

The support group can minimize risk to itself through the use of the support group meeting disclaimer. The disclaimer is particularly appropriate for a meeting in which the topic focuses on medical information, treatment, or therapy and can be stated during opening business.

**Support Group Meeting Disclaimer Example**

*The information presented at this meeting does not necessarily reflect the views or official position of the Brain Injury Association of Virginia nor carry the endorsement or support of the Association.*

*For specific medical advice, contact your physician.*

Helping the Speaker at the Meeting

A designated group member should greet the speaker as soon as he/she arrives and make sure that the speaker is comfortable. In this initial chat, ask important questions (i.e., will the speaker take questions during the presentations or should all questions be held until the end?) and include this information in the speaker's introduction.

Ask the speaker if they’d like a time check.

If audio-visual equipment will be used, a group member should check to make sure it is working prior to the meeting. If the speaker has handouts, a group member can help distribute them.

In order to allow sufficient time for the full presentation and a question-and-answer period afterwards, introduce the speaker at the scheduled time, present his/her biography, and inform the audience how the presentation will proceed. Remind everyone to turn their cell phones off.

The facilitator or someone else designated for the task should “police” the meeting. If the speaker has asked that questions be held until the end and someone interrupts with a question, the facilitator should say, “Please hold all questions until the end.” An individual with memory problems may not remember his or her question if he/she has to wait. Asking support group members to write down their questions as they think of them will help alleviate this problem.

Occasionally a presentation will run longer than planned. If it does not have a negative impact on the meeting, the facilitator should let the presentation continue. If the extended time does create a problem, the facilitator can cue the speaker that he/she is out of time. This is usually be done with a visual cue if agreed upon in advance or by walking toward the speaker and using simple hand motions to let the speaker know what it is time to conclude the presentation. The facilitator might also catch the speaker's attention and point to the clock. If that does not work, the facilitator may need to interrupt. That should be done as courteously as possible by saying something like, “I’m really sorry to interrupt you Ms. Smith, since this is such an interesting topic, but I’m afraid we’re out of time.”

On behalf of the group, thank the speaker at the conclusion of his/her presentation. If a token gift is given, it should be done at this time. This is nice but giving a gift is not essential and most speakers do not expect it. If appropriate, invite the speaker for any social activity that follows. This is not only a nice gesture, but it also gives the audience a chance to meet the speaker.

One of the host group members should help the speaker pack up materials at the close of the meeting.

Sending a thank-you note is a great way to express the group’s gratitude to the speaker as well as encourage the speaker to return and refer professional colleagues to the support group to make future presentations.
Managing Membership and Participation

Maintaining a Membership List

Members should carefully consider how the membership list will be used. While it may be beneficial to give everyone a list of fellow members so they can easily contact one another, this may lead to some problems the group needs to address beforehand. Handling confidentiality should be discussed as a group.

- Names and addresses on the list should not be shared outside the group and never without permission of the individual.
- Recognize that circulating the membership list among support group participants can open the door to unwanted or inappropriate calls from inside the group. This could be particularly troublesome when a new member of the group begins to get calls from someone he/she does not know or when a group participant receives calls at all hours of the day and night.

A good plan is for the group to circulate a membership sign-up sheet at the meeting, allowing for voluntary participation. If the list is to be distributed among the members, this should be made clear before anyone signs up. This allows those who wish to sign up to include the times during which they are available to take phone calls from other members.

Working Together

Now that the group has had its first meeting, the work of keeping a support group going can be divided or shared, especially if it is a larger group. Listed below are examples of short job descriptions which can help the group identify, define, and assign responsibilities:

- **Group Coordinator** - coordinates group functions/logistics, assigns tasks, and assures periodic review of group effectiveness
- **Meeting Facilitator** - ensures group meeting runs smoothly, promotes participation of members, and increases effectiveness of the group process
- **Contact Person** - publicizes name and phone number and accepts calls from people interested in the group
- **Welcome Person** - greets new members individually before the meeting begins, introduces new members to the group, and follows up with new members after their first meeting.
- **Publicity Director** - continuously publicizes the meetings to the community through news sources, posters/flyers, public events, etc
- **Membership Coordinator** - maintains membership roster, contacts all members by phone or mail for notification of meetings and other news

Avoid assigning responsibilities to first time attendees (unless they specifically request particular tasks for which they may be well suited). It is usually better to enlist the help of those who have attended several meetings and are comfortable in the group.
Newcomers

It is important to treat newcomers with special consideration; this may be the first time they have reached out for support and you want to make them feel welcome and encourage them to return. Keep the following tips in mind for welcoming new people to the group.

- Have a ‘welcome person’ greet the newcomer, introduce him/herself, give the newcomer a brief introduction to the group, and discuss the voluntary nature of participation.
- The first-time attendee should be introduced to the group and given a brief period of talk about him or herself, if he or she desires.
- The welcome person should ask the newcomer to complete an index card indicating whether he or she wants a follow-up phone call, visit, or more information mailed to them. This is a no-pressure way for the group to establish a second outreach opportunity.
- An invitation to the next meeting is a simple follow-up method that encourages the person to return.

Group Size

The group size may vary drastically over time. Be it small or large, the group size does not necessarily affect the success of the group. Small groups of 5-10 people can be an excellent forum for honest expression, camaraderie, and deep learning.

A skilled leader and facilitator can effectively manage large groups of 10-15 people; however, a large group of 20 or more may be too diverse or simply too big to allow for truly supportive, inclusive discussion. The facilitator must be ready to handle a large group if necessary, or make the decision to split the support group into smaller, more intimate units. Before splitting the support group for the supportive session, the facilitator should consider the following:

1) How will the group be split? It depends upon the group make-up, but generally a large group which includes at least two people from each “subgroup” can break up for the supportive session. For example, family members and individuals with brain injury can meet separately, spouses can meet separate from parents, or people with brain injuries could meet apart from those who have sustained strokes.
2) Are two facilitators needed, and if so, are they available in the group? Which facilitator works best with parents? Which facilitator works best with individuals with brain injury? Can one group self-direct?
3) Are there two rooms available at the meeting location? Meeting in separate rooms will minimize distractions and noise levels and facilitate more open discussion in the two groups. If only one subgroup must move to another room, then it should be the people with fewer mobility impairments.
4) When will the separate sessions begin and end? Determine this ahead of time. For example, the entire group could go over “new business,” separate for supportive discussions, and reconvene at the end of the meeting for a social period.
Expanding the Group - Continuing Publicity

This is perhaps the most overlooked step in keeping a support group going, however, attracting new members is crucial to the group’s survival. Also, educating the community about the support group can spark awareness of brain injury. Publicizing the group is an ongoing task for which at least one or two group members should formally take responsibility. Support groups should continue to reach out in as many ways as possible. Everything the group does to announce its existence to the community will help make the group more successful.

Transitions Among Membership

Group members will come and go as their needs are met or as their life circumstances change. Transition is normal and healthy for a group. One thing that should remain consistent is the meeting format. Although attendance, speakers, or special events may alter the format occasionally, a ‘typical’ format will maintain the supportive nature of the group.

No matter how good the support group may be or how well it meets the needs of the members, it is inevitable that people will leave the group. In many cases, this is a very positive step and it means the individual has moved forward in his/her life and recovery process. While there will be a sense of loss within the group, the members should be positive about someone’s ability to take this step.

When someone does leave, it may be important to learn why he/she left. Knowing the reasons will help the group determine how it can improve for the future. While there is usually some sense of failure when someone leaves due to a problem he/she has with the group or because of unmet needs, those individuals remaining in the support group need to recognize that they may not be able to provide what everyone needs or wants.

Group transitions are a topic for the members to discuss with the help of the facilitator. A good facilitator can help the group discuss someone’s leaving, as well as everyone’s feelings about it - good, bad, sad, or otherwise - while maintaining a productive focus.

Sometimes, the reasons for leaving the group are not positive. This is not always the fault of the group; it may be simply that the group process was not the right thing for a particular person or family.
Meeting Individual Needs and Avoiding Stagnancy

Over time, the needs of the longest-standing group members can change. With thoughtful planning and careful execution, the same group can meet the changing needs of a variety of people. First and foremost, the group needs to be aware of the changing needs of the members in order to be able to successfully address them. The best support groups maintain consistency through the transition of the members as well as flexibility that helps people move forward.

When a group is not flexible, staleness may set in. If this occurs, occasional diversions can help members stay motivated, develop stronger interpersonal relationships, and attract new people.

Ideas for Alternative Gatherings

1. Guest speakers from the community can talk about current programs or issues. A motivational speaker or a panel presentation would be good alternatives. Schedule speakers who invite audience interaction.

2. Creative exercises can stimulate the group. For example, the group could read an especially good book outside of the meeting and come prepared to discuss it.

3. Recreation can be refreshing and foster team spirit. A pool party, bowling, a picnic, a spaghetti dinner, or holiday celebration work well for brain injury support groups. An open house or similar event is a great way to attract new members, provided it is well publicized. Plan events that are inexpensive, simple, easy to put together, and easy to clean up after!

4. Relaxation exercise and activities like guided imagery or Tai Chi are popular.

5. Changes of scenery or orientation can dramatically change a group meeting. For example, sitting in a circle can enhance interaction. In good weather, holding the meeting outside may pep up everyone’s mood.

6. Group members could spend a session sharing personal photographs to learn more about each other; this visual exercise is especially helpful for individuals with limited communication skills.

Whatever creative twist the group takes, the desired effect is inclusion of all group members in the group process. Everyone has his/her own communication style and own place of importance in the group. Be sure to plan ahead with agreement of members and communicate changes in meeting format so group members know to expect something different.
Evaluating the Group

Another remedy for the “support-group-gone-stale” is an evaluation that can be in the form of a discussion or, if confidentiality is a concern, a written assessment. The leadership or an ad hoc committee can take on the task of surveying the group members about the effectiveness of the support group. This survey can include both current attendees and members whose attendance has decreased. The survey should elicit opinions on:

- The group logistics (convenience of time and location).
- The supportive aspect (e.g., facilitation, confidentiality, and productivity).
- Suggestions for improvement.

In reviewing and responding to the results, the administrator(s) of the survey must consider what the group members want their group to be. It is essential that the members have ownership of the support group. It may be necessary for the support group to look beyond their own group and examine the strengths and weaknesses of other support groups in determining how to progress.

An ad hoc committee can consider reading group manuals, meeting with other group leaders, and visiting other support groups to gain information about successful support group functioning. This research will likely show that while support groups are as individual as their membership, there are some common characteristics of successful groups.

**Signs of a Strong Support Group**

- Consistency in meeting time and place
- A frequency of meetings (at least monthly) that captures interest and maintains gains in participation
- A format focusing on the support group meeting and including a brief amount of time for business
- A coordinator with the ability to delegate responsibility and coordinate activities
- A facilitator with a solid sense of self who is confident and skilled in helping people discuss feelings and resolve conflicts
- A positive, progressive tone encouraging people to move forward
- Cohesion, as evidenced by group members who have something very important in common (brain injury) and who bond through group participation
- Evolution through the loss of regular members and the addition of new members

As a result of acting as a support group leader, leaders will:

- Feel helpful to members.
- Recognize limits of skill to deal with problems faced by persons with brain injury and their families.
- Ask for assistance in working with members.
- Receive help in working with members.
- Learn skills to be more effective leaders.
As a result of participating in a support group, members will:

- Know how other people deal with their brain injuries.
- Gain support from and give support to other group members.
- Recognize the many ways that brain injury affects people (e.g., deficits, behavior, resulting conditions such as a seizure disorder).
- Know how brain injury affects self, family, and friends.
- See the brain injury as relevant and useful to self.
- Learn and use new adaptive strategies for managing brain injury symptoms.
- Know education and service programs available from BIAV.
- See support group programs as relevant and useful.
- Be given access to other support groups as well as educational opportunities.
- Know about and use community resources learned about in the support group.


**Support Group Measurement Strategies**

To measure the success your support group, you may want to periodically evaluate the effectiveness of these components:

**Outputs:** Including, but not limited to, number of meetings held and the number of participants served.

**Outcomes:** Describes the difference a program makes in people’s lives such as new knowledge gained, changed attitudes or values, or modified behavior.

Outcomes express the expected impact of the program. Examples of methods you may use to measure outcomes are:

- Surveys that measure changes in attitudes, feelings, and self-confidence.
- Surveys of knowledge gained in support group.
- Written program surveys (i.e., questions in which participants indicate the degree to which they agree with the statements in relation to their participation in the group.)
- Focus groups.

BIAV can help your group with evaluations.

**Assessment Strategies for Support Group Leaders**

Most leaders welcome the opportunity to maximize the effectiveness of their group. Leaders can become aware of the group’s needs and areas in which to seek new direction through the measurement process. Group leaders and members can use the following suggestions to gather information about their group’s status:

- Complete the outcome measurement tools and talk about the results as a group.
- Use the “Is My Group Healthy?” questionnaire (at the end of this section).
- Schedule a specified group meeting to talk about how the group is meeting the needs of members and any changes that may need to be made.
- Inform members that BIAV staff and support group leaders are available and open to guide communication about any aspect of the group.
Leaders can also use the following evaluation process:

- **Observe** the group while the meetings are in session.
- **Ask group assessment questions** of group members
- **Discuss** with the whole group ways to make the group more effective.
- **Decide** to try a new idea to see if it works and then re-evaluate to see if it accomplished what you had hoped.

**Group Assessment Questions to Consider Together**

- What would you like to see changed in the group? What steps could be taken to make that happen?
- How can group leadership opportunities and responsibilities be shared?
- How can the group’s communication and relationship with BIAV and other support groups be improved?

## Is My Group Healthy?

<table>
<thead>
<tr>
<th>People in our group are comfortable talking about themselves.</th>
<th>Our group does this well</th>
<th>Our group could use some improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group members talk about how they feel emotionally.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members give each other positive feedback.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members listen to each other well.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members learn ways to deal with feelings.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members are encouraged to help themselves.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our group welcomes new members.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group meetings include humor and laughter.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members feel more informed and empowered when they leave our group.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hope is generated within our group.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our group functions the way I, as a leader/member/facilitator, would like.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I leave our group feeling good about it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable in my role as a group leader/facilitator/member.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Each person talks or participates in some way.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our group is positive, yet able to deal with problems.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Funding the Support Group

A brain injury support group can be a cost-free endeavor, so funding may not be an issue. If any cost is involved, it will probably be minimal, covering such items as refreshments, printing, postage and rental fees for the meeting space. While in many cases, the people who form the group are willing to cover these costs in the beginning, it is unfair to ask them to continue to do so. While members of a support group may share expenses of running the group, attendance is always FREE; there is no joining or registration fee.

One common expense is the distribution of flyers and announcements. Many people now use email and this is a quick and cost-effective way for members to communicate. Attachments may be difficult for some to open. Placing information in the body of the email can ensure everyone receives important information.

Support group members can each take turns paying for the purchase of supplies or materials. If people take turns doing this, it’s probably a good idea for someone to keep track. However once the group grows, this really isn’t a practical solution over the long run. So before the first dime ever changes hands, the group will have to discuss how it wants to handle money.

Internal Management of Funds

The group may decide to contribute or receive donations of money or supplies, and use them in whatever manner they choose. However, this may not be a good option as it has the potential to create big problems for the group for many reasons.

- These kinds of funds usually come as cash.
- Making sure that more than one person can access the money can be problematic.
- Members controlling the money have to be accountable to others in the group.
- The funds may not be used for the purposes for which the donation was intended or in a manner that benefits the group.
- Unless the group has tax-exempt status, it cannot offer tax deductions to donors.

If internal management of funds by the group is the way your group decides to go, BIAV should not be listed on any bank documents if an account is opened and BIAV will in no way be responsible for any mismanagement of funds handled internally by the support group.
Did You Know?

There are IRS rules on documenting goods and services that donors receive in exchange for donations, record keeping rules imposed on donors of charitable contributions, and disclosure rules imposed on charities that receive certain contributions. These rules include the following:

- A donor must have a bank record or written communication from a charity for any monetary contribution before the donor can claim a charitable contribution on his/her federal income tax return.
- A donor is responsible for obtaining a written acknowledgment from a charity for any single contribution of $250 or more before the donor can claim a charitable contribution on his/her federal income tax return.
- A charitable organization is required to provide a written disclosure to a donor who receives goods or services in exchange for a single payment in excess of $75.
- Corporate donors should consult their finance office or tax advisor to determine what is charitable and what is a business expense. Do not offer or suggest to a business or corporation what portion of their sponsorship/gift is tax deductible. You can provide corporate sponsors with information about real costs for events such as ticket costs, food and beverage, signs, etc.

Sponsorship and In-Kind Donations

When a support group is seeking help to offset expenses, it helps to know the distinction between sponsors and in-kind donations.

- A sponsorship is a comparatively large monetary contribution that is not targeted for a specified expense but rather helps to increase overall revenue. Benefits are promised to the donor such as recognition, printing in a flyer, etc.

- In-Kind Donations are donations of products or services instead of money.

There are specific rules and procedures for accepting sponsorships and in-kind donations if you plan to provide a tax deduction to a donor.

Please stay informed.
Considerations for Seeking Sponsors/In-Kind Donations

- Some places that may act as sponsors or provide in-kind donations are local hospitals, rehabilitation programs, and professionals involved in brain injury (e.g., therapist, doctor, lawyer, medical practice).
- Be clear about what the sponsor/donor is providing. For example, a sponsor may underwrite the cost of a mailing, but will they print the flyers? Who will address the envelopes?
- Is it a one time or an ongoing commitment?
- What does the sponsor/donor expect in return? Is recognition of their assistance to the support group sufficient?

**If the sponsor/donor provides brain injury-related services, it is essential that there be no assumption that referrals will be provided in return for the sponsorship/donation. The group must remain independent and the members should be free to express their opinions, even when those opinions concern sponsors or donors.**

**NOTE:** The group should keep in mind that having a single sponsor/donor who provides brain injury services may discourage the support of other brain injury service providers.

How BIAV Can Help

Due to increasingly complicated IRS laws and to make sure everyone is protected, BIAV can assist Support Groups with donor management, provide the group with an avenue to accept tax deductible donations, and exercise oversight of the process under certain conditions.

In order for donors to receive a record of a tax deductible donation from BIAV, the donation must be received and acknowledged by BIAV. Monetary donations must come directly to BIAV; in-kind donations can come to the support group, so long as the group provide the donor information to BIAV.

Here is a short explanation of how the process will work:

- **Monetary Donations:** Any money donated for a particular support group will be held in a BIAV account, which the group can access in a couple of ways:
  - **Re-payment of expenses:** If someone buys supplies, refreshments, or pays for postage, all they need to do is send the BIAV expense reimbursement form and a copy of the receipt to BIAV and we will send a reimbursement check.
  - **Written request:** If the group needs cash in advance of a purchase, a written request that outlines what the funds are for and the expected amount of the purchase must be signed by the support group coordinator and two other members of the group. The check will be released to the requester, who is responsible for returning a receipt to BIAV after the items are purchased. If there are funds left over from the advance, the requester will be required to reimburse that difference to BIAV when the receipt is returned. BIAV will not advance any funds in excess of a support group’s available balance. BIAV will also not reimburse requestors who have not sent in outstanding receipts from previous requests.
The BIAV office manager will provide biannual account updates to each support group coordinator on record; additional updates can also be requested by the coordinator.

The BIAV office manager will assess each account a 2% charge on the total of the balance amount at the end of BIAV’s fiscal year (June 30) to cover BIAV’s administrative costs associated with providing this benefit to our support groups.

- **In-Kind (Non-Cash) Donations:** The IRS allows nonprofits to account for donated services or materials/supplies that would typically need to be purchased if not provided by donation. Allowable donated services include those that require specialized skills or the time contributed by persons that provide the benefit of knowledge, time, and experience. An in-kind form is required to receive this type of donation.

  - The In-Kind forms should be filled out by:
    - Presenters at support groups
    - Professionals that provide a service to the support group
    - Volunteers (e.g., support group leaders)
    - Individuals and organizations that provide supplies and materials (e.g., camp, golf give-aways)
  - BIAV will provide acknowledgement of in-kind donations upon completion of the BIAV In-Kind Contribution Form; contact us for the form and details

**Fundraising for Your Group**

Remember that the purpose of the group is support. Fund-raising, while necessary, should be viewed only as a means of keeping that primary activity going. Also, BIAV may conduct a statewide fundraising effort from time to time, and your support group may be able to participate in and benefit from these events.

If your support group decides to conduct an independent fund-raising campaign, a committee might take on the task. While it is not recommended for a new support group, a special event is a great way to raise funds to cover expenses and can also be a terrific social opportunity. The possibilities are almost endless with the only constraint being the imagination of the people in the support group and the people power available to plan and execute the event.

- The group might ask a merchant to donate a piece of jewelry that could be raffled off through sale of tickets at $1 each.
- In many communities, groups can sell books of discount coupons for restaurants and stores (e.g., Entertainment books).
- Bake sales, yard sales, and car washes are also possibilities that offer fun and income.

*If a special event is planned, the best advice is to make it simple, small, and enjoyable.*

For example, a bike-a-thon may sound like a great event, but if no one in the group is involved in biking, it will be difficult to come up with the right connections and learn everything that might be required. Even a car wash will require several sets of willing hands available to do the work. You’ll need the commitment of enough members to be able to successfully organize and run the event.
The Brain Injury Association of Virginia is here for you to provide guidance, information, and contacts that will help you start and maintain a successful brain injury support group in your area. We wish you well and hope this guide serves to assist you and your group as you begin this journey of mutual support. We welcome your comments and any additional information you think might be valuable additions to this guide.
Appendices
References


Resources

Brain Injury Association of Virginia
1506 Willow Lawn Drive, Suite 212
Richmond, VA 23230
Phone: 804-355-5748
Toll-Free Help Line: 800-444-6443
Fax: 804-355-6381
www.biav.net

Resource Request Form - To receive information from the Brain Injury Association of Virginia’s clearinghouse, visit our website and click on the “Learn About Brain Injury” tab to fill out our online resource request form or print a copy to mail into BIAV.

Brain Injury Association of America
1608 Spring Hill Road, Suite 110
Vienna, VA 22182
Phone: 703-761-0750
Fax: 703-761-0755
www.biausa.org

Useful Brain Injury Web Links
The following links are provided for your convenience. BIAV is not responsible for the content of any linked pages and does not endorse products or services that may be offered by these sites.

General Information

www.brainline.org Brain Line, provides information about the effects of, living with and preventing brain injury

www.pubinfo.vcu.edu/pmrnrc National Resource Center for Traumatic Brain Injury, hosted by Virginia Commonwealth University’s Medical College of Virginia, part of the TBI Model Systems Program, includes frequently asked questions, reference materials, and an advice column

www.craighospital.org/TBI/HealthandWellness.asp The Rocky Mountain Regional Brain Injury System, hosted by Craig Hospital, Englewood, Colorado, part of the TBI Model Systems Program, includes articles on topics they have researched

www.mssm.edu/tbicentral/resources/index.shtml TBI Central, hosted by the Mount Sinai Medical Center, the NY State Model Systems Program, contains consumer reports for survivors and family members as well as resources for professionals, researchers and service providers

www.neuroskills.com  Centre for Neuro Skills, TBI Resource Guide, research articles, can subscribe to a monthly newsletter

www.dana.org  The Dana Foundation, gateway to all kinds of brain information

www.headinjury.com  Head Injury Hotline, links to journals, current research, law, advocacy, family and child resources, and locating service providers

www.tbiguide.com  TBI Survival Guide, offers practical information on common consequences of brain injury, including physical, cognitive and emotional issues along with suggestions for coping strategies

www.naric.com  National Rehabilitation Information Center for Independence, funded by the National Institute on Disability and Rehabilitation Research; has a disability information center, and links to research projects

www.tbigrdsc.org  TBI Model Systems, provides information on programs, projects and associated publications through the Traumatic Brain Injury Model Systems

www.med.harvard.edu/AANLIB/home.html  The Whole Brain Atlas, information on acquired brain injury and informative pictures

www.lapublishing.com  Lash and Associates, company with tip cards, books, and manuals related to brain injury in adults and the education of students with brain injuries

www.tbihome.org  several message boards on one site, some for people with a brain injury, some for family/caregivers, children, etc.

Family Issues


www.caregiver.org  The Family Caregiver Alliance, information and resources for caregivers including practical tips for long term care and an online caregiver support group

www.familyvillage.wisc.edu  Family Village, information, resources, and communication resources for persons with cognitive and other disabilities and their families

http://mayoresearch.mayo.edu/mayo/research/tbims/guide-for-families.cfm  Booklet from The Mayo Clinic to help families learn more about TBI

www.caregiving.org  National Alliance on Caregiving, offers tips for caregivers, products, resources, links to other sites.

www.caregiver.com  Online version of Today's Caregiver Magazine
Pediatric and Education Issues:

http://www.virginialac.org  The Center for Special Education Advocacy, independent, private, not for profit, tax-exempt corporation formed by advocates dedicated to improving educational services and outcomes for students with disabilities

www.cec.sped.org/erice.htm  ERIC Clearinghouse on Disabilities and Gifted Education, database on a broad range of education issues for educators, librarians, counselors, administrators, and families

www.projectlearnet.org/ LearNet, on-line problem-solving system for teachers, parents, clinicians and students with useful procedures for helping students with brain injury in school and at home

www.ldavirginia.org  Learning Disabilities Association of Virginia, information about state special education regulations, advocacy training, and more

www.nichcy.org  The National Information Center for Children and Youth with Disabilities, provides information on disabilities and disability related issues for families, educators, and other professionals, with emphasis on children and youth

www.peatc.org  Parent Education Advocacy Training Center, assists the families of children with disabilities through education, information, and training


www.wrightslaw.com  Wrightslaw, accurate, up-to-date information about special education law and advocacy for parents, advocates, educators, and attorneys

Government Agencies/Benefits

www.disability.gov  Disability Direct, online access to resources, services and information available through the Office of Disability Employment Policy, U.S. Department of Labor

www.govbenefits.gov  Interactive site that helps you determine if you are receiving all the benefits you are entitled to

www.dmas.virginia.gov  Site for the Virginia Department of Medical Assistance Services, the agency that oversees Medicaid services throughout the state, including waiver services

www.medicare.gov  Provides information on finding participating providers, understanding what is and is not included in Medicare coverage and how to fill the gaps.

www.ssa.gov  Provides information on the programs administered by Social Security

www.easyaccess.virginia.gov  Virginia Easy Access, public private partnership with the Commonwealth of Virginia, SeniorNavigator, and 2-1-1 Virginia, assists seniors, adults with disabilities and the providers that support them to find services
www.olmsteadVA.com Virginia Olmstead Task Force, details Virginia’s plan to meet the requirements of 1999 U.S. Supreme Court decision, that under the ADA, a State must provide community-based services to qualified individuals and must make “reasonable accommodations” in its programs to do so

www.vadars.org Department of Aging and Rehabilitative Services (DARS), describes the services available from this state agency including vocational rehabilitation services, brain injury services, and community services

Advocacy

http://capwiz.com/bia/home Brain Injury Association of America’s: public policy updates and action center for contacting elected officials that represent you

www.house.gov/writerep Service provided to assist you in finding and contacting members of the US House of Representatives

www.senate.gov/general/contact_information/senators_cfm.cfm Service provided to assist you in finding and contacting members of the US Senate

Other Information

www.VaCollegeQuest.org Virginia College Quest, project of the Virginia Department of Education Training and Technical Assistance Center at George Mason University and The Advocacy Institute, offers information, resources, and activities to help prepare middle and high school students with disabilities for transition to college

www.dredf.org Disability Rights Education and Defense Fund, Inc., protects and advocates for civil rights of people with disabilities

www.jan.wvu.edu/media/BrainInjury.html Job Accommodation Network, provides information about job accommodations, the ADA (Americans with Disabilities Act), and the employability of people with disabilities

www.worksupport.com VCU Rehabilitation, Research and Training Center on Workplace Supports, topics include disability management supported employment, accommodations and the Americans with Disabilities Act (ADA)

www.abledata.com Abledata, federally funded project providing information on assistive technology and rehabilitation equipment

www.vats.org Virginia Assistive Technology System, statewide project committed to improving the quality of life for all Virginians by increasing awareness and accessibility of assistive technology