SUPPORT GROUP GROUP LEADER TRADER TRAINING MANUAL



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INTRODUCTION

This manual was developed by the Brain Injury Association of Virginia (BIAV), the only statewide association in Virginia dedicated exclusively to advancing education, awareness, support, treatment and research to improve the quality of life for all people affected by brain injury.

As part of this mission, BIAV leads support groups for Virginians impacted by brain injury and is also a resource for externally-operated support groups. A support group is a gathering of people with common experiences and concerns who meet together to provide emotional and moral support for one another. These groups encourage a sense of community, a source of empathetic understanding and provide an avenue for establishing social networks¹.

The purpose of this support group leader manual is to provide a framework for starting and operating a successful support group. The information in this manual is applicable to both new and seasoned support group leaders.

What can BIAV do for your support group?

BIAV can provide your support group with:

- A wealth of information and resources: 1-800-444-6443 *info@biav.net * www.biav.net
- Information regarding other support groups in your area
- Connections to people seeking to join a support group like the one you plan to start
- Technical support
- Training for support group leaders
- Peer connections to other support group leaders and brain injury professionals
- Suggestions for topics of interest and possible speakers for your meeting
- Answers to questions posed by members of your support group
- Information on the latest developments regarding brain injury legislation and policies in Virginia

HELPFUL DEFINITIONS & CLARIFICATIONS

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 brain injury 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.

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, while beneficial, can dilute the mission of the wgroup 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 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.

RESOURCES FOR STARTING A NEW GROUP

START A GROUP IN 5 STEPS

Form a Leadership Team: this typically consists of a Facilitator and a Coordinator. Sometimes the facilitator and coordinator are one and the same person.

Determine meeting style: open-ended or pre-planned topics.

Determine group purpose and structure: Is it for caregivers only, persons with a brain injury, led by a professional or a peer, or a combination of these things? Is the focus on adults, children, mild or severe brain injuries? Will there be an educational and social component in addition to peer discussions? If time for socialization is provided, will snacks be offered and if so who is responsible for coordinating?

Establish a meeting place and time.

Inform BIAV about your support group by emailing info@biav.net or calling 804-355-5748.

A COORDINATOR'S ROLE

A coordinator deals with the practical and operational details of running a support group and acts as a liaison to BIAV.

Responsibilities:

- Schedule group times
- Secure appropriate meeting space
- Communicate with current and potential members and give announcements during meetings
- Delegate activities/responsibilities to members
- Publicize group
- Communicate changes to BIAV

Necessary Skills:

- A strong understanding of brain injury and its impact on individuals and families
- The ability to clearly communicate with patience and respect
- The ability to recruit, guide and encourage members in roles that match their strengths
- The ability to utilize organizational skills to manage the logistics of running the group



Note: The coordinator role can be shared by more than one person. Sometimes, if resources are limited, the coordinator and the facilitator are the same person.

A FACILITATOR'S ROLE

The facilitator leads the discussion and presentation portions of the support group session while striving to make meetings productive for all members.

Responsibilities:

- Review and enforce group conduct rules and boundaries during meetings.
- Guide the direction of the discussion with suggestions, questions and relevant feedback to keep the group progressing and on topic.
- Balance participation across members by skillfully prompting less vocal members to participate and limiting the conversations of dominant members.
- Model the behaviors you want to elicit from the members such as empathy, emotional openness, encouragement, feedback and acceptance.
- Interpret group interactions by highlighting parallels in participants' experiences and summarizing conversations for clarity and applicability to group topics.

Necessary Skills:

- Strong understanding of brain injury and its impact on individuals and families.
- Ability to focus the group on task while still being flexible and patient.
- Ability to maintain confidence and composure when confronted with intense feelings such as denial, hostility and blame.



Note: It is advised that facilitator(s) secures a mentor or therapist outside of the group in order to process their own feelings. A facilitator should not process their feelings within the group they are facilitating. Refer to the section on self-care.

5 SIMPLE LEADERSHIP TIPS



Keep meetings positive and encouraging: 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 and self-pity session. When a problem is presented, encourage other members to come up with positive ways to deal with it. While modeling this positivity, remember to listen and reflect more than you talk or problem solve. As the leader your job is make people feel heard and supported.



Develop a leadership support system: Leadership is a lot of pressure, and requires you to focus on others' problems while abstaining from talking about yours. Find other encouraging leaders and friends to talk to about personal struggles, leadership skills, ideas, and to troubleshoot problems.



Set limits and stick with them: Set yourself up for success and avoid burnout by setting firm availability times for your support group members. For example: "I am available for phone calls Tuesday-Thursday between the hours of 4-7 and will answer emails within one day."



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 a delegator: Make it clear to the group that everyone needs to claim ownership and participate in the necessary tasks. When you find a group member who exhibits leadership qualities, consider training/mentoring them and assigning responsibilities.

THE IMPORTANCE OF SELF-CARE

Managing the well-being of a support group starts with overall wellness of the facilitator. It can be very challenging to lead a support group and care must be taken to address burn-out and compassion fatigue. There may be times when the support group leader needs to remove themselves from their role to practice self-care in order to ensure the overall health of the group.

If you as a facilitator and/or coordinator notice signs of anger, irritation, sadness, lack of objectivity, and an inability to set boundaries within your group, you may need to step back from your role to take time for yourself. If you maintain healthy boundaries and practice self-care as a matter of routine, it is far less likely the signs mentioned above will become problematic. Easy ways to practice self-care include focused breathing, exercising, listening to music, creating art, talking to a friend or professional, eating well, and meditating.

Remember: self-care is not selfish. It is ethical to practice self-care so you can effectively support others.



PROFESSIONAL V. PEER LED GROUPS

There is no right or wrong approach here - choices depend upon the participants' preferences about professionals as well as the availability of an appropriate and willing professional. Peer facilitators are people who have been personally impacted by brain injury.

Brain Injury Professionals Provide:

- Strong organizational skills to plan 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 persons with brain injuries must navigate (government, healthcare systems, etc.).
- Connections to community resources and other professionals (lawyers, doctors, etc.).

Peer Led Groups Provide:

- Relatability to someone with a shared experience.
- A level of comfort Participants may feel only someone who has lived through a similar experience can understand what they are expressing during meetings.
- Personal investment There may be a perception a professional is in it for referrals, resumebuilding, etc.
- A safe space for participants to openly express feelings about other professionals, even if those feelings are negative.

MEETINGS

Choosing the Type of Meeting

The next step is to choose the format of the meetings for your new support group. Typically two types of meeting formats are utilized: open-ended and on-topic. Some groups will work best with a mix of both open-ended and on-topic sessions.

Open Ended Meetings:

- Are casual, loosely planned meetings.
- Provide discussions initiated by a facilitator and/or members with group participation at each meeting; discussions deal with current issues, problems, ideas, thoughts, emotions, etc.
- Need a good facilitator.

On-Topic Meetings:

- Are formal, pre-planned meetings.
- Are based on the predetermined needs of the group including the topic to be discussed.
- Make pertinent, informational material available (flyers, informational packets).
- Require pre-planning and organization

Choosing a Time and Place

When choosing a time and place for the meetings, consider the people who are interested in your group and what will accommodate most of those people.

Choosing a Time: Keep the meeting time consistent. This will help people with memory difficulties or very busy schedules to attend meetings regularly.

Things to consider:

- Child care and respite care needs
- Availability of transportation
- Work schedules of group members and facilitators
- Traffic
- Distance to and from meeting place for most members

Potential locations:

- Church fellowship hall
- Recreation Center
- Multi-purpose room
- Library conference room
- University lounge
- School meeting room
- YMCA meeting room
- Service organization facilities (Civitan Club, Kiwanis Club, Moose Lodge, Knights of Columbus, etc.)

Publicize the First Group

A simple publicity plan will help launch the group, laying the groundwork for a successful first meeting and a continuous community presence. Generally, announce the group at least thirty days prior to the first meeting.

Publicity Plan Steps:

- 1. Develop an announcement flyer (digital and/or hard copy). Include the group name, time and place of meeting, purpose of the group and contact information for the coordinator.
- 2. Call or email BIAV and ask them to publicize your group
- 3. Deliver flyers to the following places in your area:
 - Doctor's offices, rehab facilities
 - Home care agencies, outpatient clinics
 - Social services offices
 - Vocational rehabilitation agencies
 - Civic organizations
 - Therapy, counseling centers
 - Domestic violence programs
 - Local VA hospitals
 - Libraries
 - Coffee shop community boards

Post an announcement on various social media pages such as Facebook, Nextdoor, Instagram, Meetup and Twitter.

Be careful to never break confidentiality by identifying members of the group. For example, do not tag any member of the group on social media without permission. (See Considerations for Social Media and Technology.) A sample announcement is included on the next page.



RESOURCES FOR ESTABLISHED GROUPS

IMPORTANT CONSIDERATIONS

There are many important aspects of the group that need to be considered, discussed and agreed upon by the group before proceeding. This includes support group etiquette, conflicts, ethics, diversity, and legal considerations.

Support Group Etiquette

For the group to function productively, participants will need to observe some basic rules of good group behavior. Participant should decide these rules as a group, as they will be more committed to following them. Things to consider could be a smoking break 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.

Here are some ideas to get you started: (Consider choosing 5-7 rules that best fit your group dynamic.)

Support Group Ground Rules:

- No cursing.
- 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.

Other Rules to Consider:

- Respect everyone's privacy; what is said in the group stays in the group.
- Refrain from having side conversations during the meeting.
- Talk about ourselves or our own situations, not others.
- Suggest and support, do 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 feeling.
- 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.



Note: It is important to agree on a clear consequence for not following the adopted rules. For example: 3 strikes you're out; suspension, expulsion, etc. For more information, review the Ethics section.

Conflicts Within the Group

At some point, the support group will experience a conflict. Being prepared is the most effective way to resolve the issue. There are three main areas to hone in on:

- 1. Building an awareness for potential triggers and addressing them can prevent a lot of conflicts.
- 2. Diffusing the situation in the moment helps keep the group safe and functional.
- 3. Aiding the affected individual(s) develop a plan of action can lead to success in future groups.



Proactively Addressing Triggers:

- 1. Prevent the meeting from getting too loud.
- 2. Address participants who are interrupting and talking over one-another.
- 3. Redirect dominating members who are over-participating.

Handling Conflicts:

1. Reflect. Validating and honoring what the individual is saying should help diffuse the intensity of emotions.

Example: "I hear you saying you felt put down. Is that right?"

- 2. Engage the Group. Check-in with the rest of the group to see what they are feeling. *Example: "I wonder if other members are feeling confused by what just happened?"*
- 3. Respond. The facilitator or group member should provide a plan or attempt at progress to bring an end to the conflict.

Example: "Okay, it sounds like we all agree it's getting too loud in here, making it hard to listen to the presentation. Do we all agree to make an effort to quiet down?"

Preventing Future Outbursts:

- 1. Recognize behavior is goal-oriented. (Try to figure out what the participant is attempting to accomplish from their behavior.)
- 2. Consider that the problem may be both an individual and group issue. (Try to see how both the individual and the group could adapt to improve the situation.)
- 3. Help the person find an appropriate way to participate. (Could they go into the hallway for a break when the room gets too loud? Could they write down their question so they don't forget it before they get called on?)

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 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.
- 2. To have a simple, common-sense approach to problems when they arise.

To Prepare:

Establish a relationship with BIAV. BIAV staff are experienced in dealing with difficult issues, legalities, liabilities, crises, etc. They should be used as resources to advise support groups regarding potential dilemmas and solutions in order to effectively respond to difficult issues.

To Approach:

Decide and write down the following:

- 1. What behaviors are acceptable and what behaviors will not be tolerated.
- 2. Clearly define the consequences of unacceptable behavior.
- 3. The limits of the support group's responsibility to attendees.

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

Example: A person comes to a meeting in crisis

Points to Consider:

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. At this point, a trained professional is required. 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. This way, a member can quickly contact the required resource when necessary.

Diversity

Individuals with brain injury and their caretakers all share a common bond. However, this is a greatly varied community with many diverse backgrounds, circumstances, ethnicities, religions, ages and levels of disability. To successfully serve individuals in this community, it is important to understand the diversity within it. Rather than presenting a problem, these differences should be viewed as enhancing the group by providing varying viewpoints that benefit everyone.

Listening is the best way to learn what someone needs and is trying to express. Never make assumptions or attempt to speak for anyone. Reserve judgment and listen.

Note: It is important for the members of the support group to:

- 1. Understand where everyone in the group is coming from.
- 2. Provide a forum for addressing specialized needs.

Some areas of diversity and considerations:

- Differences in socio-economic status: People affected by brain injury come from all socioeconomic backgrounds. Socio-economic status (SES) is not just about income it also addresses education, work, and how a person is perceived in relation to other members of society. People with relatively few resources (low SES) may not have good access to health care services, or even transportation to get health care. In your group you will encounter people with high, middle, and low SES all living very different experiences. Priorities for your group members will vary based on SES for example: while a person with a middle SES may be focused on maintaining their health, a person with a low SES may be trying to hold down two minimum wage jobs, with no health insurance benefits, just to support their family.
- **Differences in ethnic and/or religious background:** A person's ethnicity and/or their religious background can affect how they seek help.

Example 1: Some individuals may believe the family unit alone should deal with their problems. These individuals may be hesitant to join a support group, and may have different boundaries in regards to sharing and participation if they do feel comfortable enough to join a group.

Example 2: If a group is predominantly white, a person of color may feel isolated and unwelcome. The challenge to the members of the support group is to listen and make new people feel welcome and accepted.

- **Differences in level of disability:** Individuals with varying levels of disability face different challenges. An individual who uses a wheelchair or is deaf, for example, may need accommodations in order to effectively participate in the group.
- Language Barriers: If an individual would like to participate in the group, but speaks a different language, signs, or uses Braille please contact BIAV for resources on how to secure a translator for these individuals.

Legal Issues and Considerations

Awareness of legal issues and proper procedures are an important aspect of facilitating and coordinating a support group. Failure to comply with applicable laws and regulations can compromise the safety of the group and make you vulnerable to legal action.

Important areas for legal consideration:

- Use of Disclaimers
- Social Media and Technology
- Safety/Suicidal Threats

Use of a Disclaimer

It is a good idea to provide a disclaimer at the beginning of every meeting, in any handouts/emails provided and especially when any information regarding medical, psychological or legal issues is being discussed or presented.

Disclaimer Example:

Disclaimer: This is an independent support group. As such, the information presented does not necessarily reflect the views or position of the Brain Injury Association of Virginia nor carry the endorsement of the Association. For medical advice, contact your physician. For legal advice, contact your attorney.

Social Media

Social media and technology are becoming more prevalent as a means of communication and connection for groups of people needing support from individuals with similar needs. This comes with great convenience and challenges. If used properly, technology can bring a community of support groups to people who might not access it otherwise.



Ethical Considerations for Social Media:

It is very important the Coordinator(s) and Facilitator(s) clearly define the group's technology policy and discuss the impact technology can have on the group's safety.

Topics to discuss regarding technology during in-person meetings²:

- Cell phone and tablet use during meetings. (On silent? Put away?)
- Recording and photography should not be permitted unless all parties have signed waivers consenting to be recorded.
- What (if anything) is okay for group members to share on social media?
- Should the group have a Facebook page, Instagram handle or Twitter account? If so, what should be shared on it? Inspiring and educational quotes? Fundraising and advocacy information? Advertising for the group meetings?

Technology

Another thing to consider is online support groups, which have gained popularity over the last 15 years as technology has become more accessible. Benefits of online support groups include the ability to exchange information in real-time; the ability to refer back to discussions; continuous availability of support not confined by a physical meeting; and greater access for people unable to travel.

There are several platforms you can use to operate an online group – many free or low-cost - can be used to facilitate a private online support group including Facebook Groups, Slack, WhatsApp, and Google+Community.

Regardless of the platform you select, the same privacy, confidentiality, facilitation techniques, and community "ground rules" apply. Each platform will allow you to restrict membership – invitation-only membership is strongly recommended.

Additional topics to consider specifically regarding online meetings:

- Is the meeting taking place on a secure page?
- Will videos or audio be available and utilized for the whole group, just the coordinator(s) and facilitator(s), or not at all?
- Will there be a vetting process to ensure all members belong in the group and are not trolling?
- What is proper online etiquette/conduct?
- How do you ensure confidentiality in an online group? (Example: Is there a way to prevent screen-shots of individual's images and/or comments?)

BIAV can offer additional tips and resources on starting and running online groups.

Suicidal Threats/Ideation

When running a group it is important to be prepared for a participant to voice thoughts or threats of suicide. Develop a plan based on the following resources. Safety of the individual and safety of the group is top priority. Having a plan in place can help everyone remain calm and respond effectively if such a crisis arises.

Plan ahead. Keep a list of the following resources on hand at all times.

- National Suicide Prevention Hotline: 1-800-273-TALK (8255)
- suicidology.org



NEVER LEAVE A SUICIDAL PERSON ALONE

- Call the suicide prevention hotline
- Call 911 if directed to do so by the counselor on the hotline
- Notify a family member/caretaker to be with the individual

The group will need some time to contemplate and discuss their feelings relating to the crisis. Include the group in a discussion regarding feelings of helplessness and despair, allowing you to all work through this emotional experience together.



Note: Sometimes violent threats might be made toward other group members or the group in entirety. If this is the case, immediately call 911 and report the threat. Then have the group members evacuate the room.

PLANNING MEETINGS

The following pages are full of resources for planning meetings once the group has started. As always, BIAV can be contacted for additional resources if your group needs more ideas or assistance.

- General Meeting Format
- Topics for Group Discussion
- Guest Speaker Ideas
- Alternative Meeting Ideas



Opening and Introductions

Have everyone introduce themselves. This is the time for newcomers to be introduced and have the opportunity to share a little bit about themselves. An icebreaker is a great idea for giving newcomers a chance to learn people's names and introduce themselves without being singled out.



Old and New Business

Announcements and schedule changes can briefly be discussed during this time.

40-50 MINUTES

Support Group Session

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 to divide into separate sub-groups for discussion. The facilitator should formally close the meeting each time, perhaps summarizing the group's discussion.



Social Time

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. This would be a good time to offer snacks if desired. A designated volunteer should stay until the end to ensure everyone leaves safely and any clean up and security issues are handled.

Topics for Discussion

Topics for Persons with Brain Injury:

- 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 I have faced and overcome
- Challenges related to brain injury 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 family communication
- Communicating feelings and needs
- Helping family and friends to better understand my brain injury
- Ways a case manager can help

Topics for Caregivers:

- Understanding changes in behavior
- Feelings of social isolation
- How brain injury affects relationships and marriage
- 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
- Wrestling with guilt
- Overprotective tendencies
- How and when to let go
- Sleep problems
- Dealing with anxiety/depression/loneliness
- Planning for the future
- Estate planning

Guest Speakers

Hosting a guest speaker can be an informative and interesting way to shake things up for an established support group. Contact BIAV if your group needs assistance finding specific individuals.

Types of Guest Speakers:

- Neurologists
- Neuropsychologists
- Psychologists
- Psychiatrists
- Nurses
- Physical Therapists
- Occupational Therapists
- Speech Therapists
- Art Therapists
- Licensed Clinical Social Workers
- Recreational Therapists

Guest Speaker Topic Ideas:

- How do I get Social Security? What entitlement programs do I qualify for? Can I still work and receive Social Security Disability Income? (Representative from Social Security Office)
- What vocational services, recreational programs, and/or housing options are available in the community? (Virginia Department of Aging and Rehabilitative Services)
- What does the BIAV or the Brain Injury Association of America do for me? (BIAV staff)
- What about driving? (Virginia State Department of Motor Vehicles, Representative of a driving rehabilitation program)
- Legal issues such as trusts, wills, and power of attorney (Attorney)
- Substance use issues (Substance use counselor)
- Understanding Pharmacological issues (Neuropsychologist)
- Sexuality (Sex Therapist, Family Counselor, Psychiatrist)

- Music Therapists
- Vocational Rehabilitation Specialists
- BIAV Staff
- Attorneys
- Family Counselors
- Sex Therapists
- Social Security Representatives
- Authors
- Nutritionists
- Wellness Coaches

Ideas for Alternative Gatherings

Sometimes it is good for the group to mix it up! If the meetings are starting to feel stale, consider planning a special session. See ideas below:

- Guest speaker 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.
- 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.
- 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!
- Relaxation exercise and activities like guided imagery or Tai Chi are popular.
- 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.
- 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 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

LEADERSHIP SKILLS

Leadership skills are something that will develop overtime if the leadership team applies themselves. Here are some resources and descriptions for the basic skills required. For further development of skills, contact BIAV for trainings, mentorship connections, and additional resources.



Facilitation Techniques

There are many resources on using general counseling techniques to lead groups. Following 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:** Attempt to convey understanding by re-phrasing an individual's statement. This helps the individual feel heard and encourages them to continue to delve deeper into their feelings. "What I hear you saying is ____?"
- **2. Questioning:** Use this technique to get specific information and/or guide the conversation to more fruitful channels.

Examples:

- "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?"
- **3. Maintaining focus:** Frequently group members will interject comments that veer away from the topic. Redirect by repeating what the group was talking about: "You were saying you felt scared to drive again?" If the group is talking a lot, remind everyone they can socialize at the end of the group.
- **4. Reflection of feeling:** This is an attempt by the facilitator to understand a member's point of view and to communicate understanding. Example: "If I understand correctly, you feel like the doctors think you're pretending about these very real problems you still have?"
- **5. Encouragement:** This is designed to counter feelings of inadequacy or to prompt action. "You're doing fine." "You can do that." "You're okay." Or "Mmm-hmmm" "Yeah" "I see." These kind words of acceptance create a feeling of safety for individuals to share raw emotions.
- **6. Generalize:** This technique pulls one individual's experience and applies it to the group to stimulate full group participation versus one individual sharing.

Example 1:

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 her aunt come and sit with our daughter, or my neighbor lets our daughter come 'help' baby sit for an evening."

Example 2:

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?"

- 7. Information Giving: This is an important technique in a brain injury support group and one of the critical reasons the facilitator needs to have a strong understanding of brain injury. For the individual who seems frustrated with short-term memory problems, hearing 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 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 member to move forward
- 8. Blocking Inappropriate Behavior: The facilitator also plays the role of gatekeeper and 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 more 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 person causing disruption.

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 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.

Coordination Techniques

Working Together:

A support group should be the work of the group. After a few meetings begin recruiting regular attendees to take-over certain roles and responsibilities. Group effort will help the group thrive.

Job Descriptions:

- Contact Person: Publicizes name, phone number and email address and accepts calls from people interested in the group.
- Welcome Person: Greets new members individually before the meeting begins, introduces them to the group and follows up with them after their first meeting.
- Publicity Director: Continuously publicizes the meetings to the community through flyers posted on community boards, social-media, etc.
- Membership Coordinator: Maintains the membership roster, contacts all members via phone or email for notification of meetings, events or cancellations.
- Set-up Crew: Arrives at meeting site first and arranges room, makes coffee, etc.

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. They should be welcomed, introduced to the group and invited back. In addition, a follow-up email or phone call should be made if the newcomer provided their information on the contact sheet.

Group Size:

The group size may vary drastically over time. However, if a group is consistently growing, it may come to the point where it is too large to function efficiently. (Usually more than 15 people) At this point, the leaders should evaluate the best way to divide the group.

Things to consider:

- Is there enough leadership in the group a new group could break off from the original group and "plant" a new group?
- If not, can the group split up into small-groups during discussion times?
- Are there extra rooms located at the current facility? Or is a new location needed?
- How will the group be divided? Can the group be divided by roles: family members, parents, spouses, individuals with brain-injuries, etc.?

Growing:

Attracting new members is critical to the group's survival. Advertising the group by posting flyers, posting on social media, alerting relevant medical offices, attending resource fairs, etc.

Transitions/Stagnancy:

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 dependability of the group.

When a group member leaves it can be useful to follow-up with them and ask for feedback. Knowing the reasons will help the group determine how it can improve in the future. People leaving groups is not always the fault of the group. Sometimes it just could not meet the needs of the person.

Another difficult reality groups face is the death of another member. The leader is encouraged to help the group process this loss – for example, the leader could facilitate discussions about what the person meant to the group, what feelings arise from the loss, and/or an activity that honors the person who died (e.g. writing cards to the family, or donating to a charity in their honor).

If members of the group are feeling sad or angry about a member leaving of their own accords, spend some time in open discussion during a meeting to allow all of the members to process their sense of loss and frustration.

Evaluation of the Group

Measuring the effectiveness of the support group can be a useful tool for strengthening, growing and adjusting course.

Areas to evaluate:

- 1. The group logistics (convenience of time and location).
 - Track the number of meetings held and the number of participants served.³ This data can aid in assessing the group logistics.
- 2. The supportive group aspect (e.g., facilitation, confidentiality, and productivity).
 - Survey group members' thoughts on the difference the program makes in their lives such as new knowledge gained, changed attitudes or values, or modified behavior.
- 3. Suggestions for improvement:
 - 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?

Assessment Strategies:

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:

- 1. Have all members and leaders take the "Is My Group Healthy?" questionnaire. Compile data to share with group.
- 2. Schedule a specified group meeting to talk about the results and discuss any changes that need to be made.
- 3. Inform members that BIAV staff and support group leaders are available and open to guide communication about any aspect of the group.

³While tracking the number of people who attend a meeting and keeping a contact list of people who attend support groups is part of running a group, it is not recommended you keep attendance records for each meeting. These records can be subpoenaed. In order to maintain confidentiality and protect the privacy of the group members, maintaining attendance records is not recommended.

IS MY GROUP HEALTHY? ⁴

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

⁴Adapted from: Koch, K., (2008). Facilitating self-help groups: A manual for self-help group leaders. National Multiple Sclerosis Society.

IS MY GROUP HEALTHY?

- 1. Is the meeting place convenient? Y/N
- 2. Is the scheduled meeting time convenient? Y/N

3. What would you like to see changed in the group? What steps could be taken to make that happen?

4. How can group leadership opportunities and responsibilities be shared?

5. How can the group's communication and relationship with BIAV and other support groups be improved?

GENERAL RESOURCES

The Brain Injury Association of Virginia (BIAV) has a wealth of information and resources on our website: www.biav.net. Toll free information and referral line: 1-800-444-6443.

Virginia's Department for Aging and Rehabilitative Services (DARS) is the lead state agency overseeing brain injury services across the state. www.vadars.org/cbs/biscis.htm