

# TBI Support Group Facilitator Guide

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## **Introduction**

Dear support group facilitator,

Thank you for volunteering your time to help support members of the community whose lives have been affected by TBI. This manual will help you create a support group, facilitate a support group, and keep it going.

Feel free to make copies of the materials and revise them for your specific needs.

Sincerely,

Mary Kowal, Christina Johnson, and Molly Kimmel  
University of Washington Master of Occupational Therapy Students  
June 2010

## **About the Authors**

These materials were created by Mary Kowal, Christina Johnson, and Molly Kimmel, University of Washington (UW) Master of Occupational Therapy students, in conjunction with the Brain Injury Support Group Network (BISGN) of Washington State. The students received support and guidance from their faculty advisor, Janet Powell, Ph.D., OTR/L, Associate Professor of Occupational Therapy at the University of Washington and Co-director of the UW TBI Model System. We would also like to thank the many support group facilitators and members of the TBI community in Washington State who gave us valuable input on this project.

## **Purpose of Facilitator Manual**

There are many aspects to consider when starting a support group. This manual is a guide that will help you think about the elements that are necessary in starting and sustaining a group. Sections cover logistics of starting a group, ongoing administrative tasks, group dynamics, planning, resources, and media information.

The Brain Injury Support Group Network (BISGN) and three occupational therapy students from the University of Washington collaborated to develop these materials. Through a review of the literature, feedback from existing group leaders, and discussions between the students and the BISGN, this manual was created. The work of the BISGN was supported in part by a grant from the Department of Social and Health Services to provide additional support for Washington State TBI support group facilitators.

We hope you enjoy your role as a support group facilitator. We appreciate your efforts to help those affected by TBI.

## Organizational Partners

These organizations helped create this manual through grant funding associated with the Department of Health and Social Services grant number 1034-82367.

**Brain Injury Association of Washington (BIAWA):** The Brain Injury Association of Washington's mission is to increase public awareness, support, and hope for those affected by brain injury through education, assistance, and advocacy.

**Tacoma Area Center for Individuals with Disabilities (TACID):** Promoting the independence of individuals with disabilities.

**Brain Energy Support Team (BEST):** The mission of the Brain Energy Support Team is to provide support, advocacy, public awareness, education, and socialization opportunities to the survivors of brain injury and their families in Washington State.

**People First of Washington/TBI Survivor Network Development Project:** We are people first, and our disability is secondary.

**University of Washington Master of Occupational Therapy Program (UW MOT):** The program is dedicated to educating entry-level occupational therapists who will provide services to individuals and populations in a variety of practice settings.

Contact information:

BIAWA  
Administration: (253) 238-6085  
[www.biawa.org](http://www.biawa.org)

People First of Washington  
1-800-758-1123  
[www.tbisn.org](http://www.tbisn.org)

TACID  
(253) 565-9000  
[www.tacid.org](http://www.tacid.org)

UW MOT  
(206) 598-5436  
<http://rehab.washington.edu/education/degree/ot/>

BEST  
(253)-426-5735  
[www.brainenergysupportteam.org/index-1.html](http://www.brainenergysupportteam.org/index-1.html)

# Starting a Support Group

## What is a TBI Support Group?

A support group is a place to share stories and activities related to traumatic brain injuries (TBI). It may be led by someone who has training in support groups and/or someone who is a TBI survivor. People who attend may include TBI survivors, caregivers, family members, friends, or those who work with survivors as part of their job.

It is a place where members can:

- **Find** out more about life with a TBI
- **Share** their own experiences during both difficult and successful times
- **Learn** from other members' achievements and strategies
- **Find** out about the newest trends and information related to TBI
- **Feel** supported by having peers around you who have gone through similar situations
- **Be** safe, knowing that everyone in the group supports each other and that what is shared remains in the group
- **Develop** relationships with other people who have had similar experiences
- **Socialize** and develop friendships
- **Get** involved with the community

## What Makes a Good Facilitator?

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

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

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

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

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

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

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

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



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

**Behavior management:** Knowing what to do when people disagree or when someone talks too much helps keep the group focused on the topic instead of the communication problem. *See page 52 for behavior management strategies.*

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

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

## Benefits for Facilitators

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

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

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

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

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

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

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

## Getting Started

Starting a support group requires effort and determination, but it can be a very rewarding experience. Here are some steps that are recommended. However, you may carry them out in a different order depending on your situation.

First, find out if there is already a TBI support group in your area.

- **Contact local medical facilities.** Call or visit local hospitals and rehabilitation centers to ask professionals who work with individuals with TBI about support groups in the area.
- **Contact local community organizations.** Contact your state Brain Injury Association and other disability-related organizations. The Disability Resources Monthly has a listing of organizations by state that can be found at <http://www.disabilityresources.org/DRMreg.html>.

If you discover that there is not a current support group in your area, you are on your way to starting one. The next steps involve making connections with people who might want to attend the group and to find out if anyone would be willing to help you plan it.

- **Contact your state Brain Injury Association.** Ask if they offer support in helping start TBI support groups. If they do not, ask if they can refer you to other community organizations that work with people with TBI.
- **Contact medical facilities and organizations.** Explain that you are starting a group and ask how you can be connected with people with TBI.
- **Talk with friends and relatives.** Explain that you are starting a TBI support group. Ask them to spread the word to their co-workers and neighbors.

## Support Group Development

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

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

- *Secretary:* This person would take notes during support group meetings. When establishing this role, work out a plan to protect the confidentiality of group members. For example, the person can take notes in a notebook during the meetings and hand the information back to the facilitator at the end of each meeting to be kept in a secure location. No names will be referenced in the notes.
- *Communications Coordinator:* This person can assist the facilitator in making reminder phone calls to members, advertising the meetings, and providing outreach to new members.
- *Back-up Facilitator:* This person can help the facilitator plan the agenda. This person could also facilitate meetings if the regular facilitator cannot be there.

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

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

**Make a list of possible places to meet.** Generally, it's helpful to search for a location that will be private and comfortable for members. Suggested meeting locations include:

- Hospitals, rehabilitation centers, and disability centers
- Senior/community centers
- Coffee houses with quiet meeting rooms
- Civic organizations such as Kiwanis and Rotary Clubs, YMCAs, and nonprofit organizations
- Libraries, universities, churches, or synagogues

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

**Use a planning worksheet.** Make copies of the worksheet on the next page to discuss with the contact at each possible location.

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

On the next page is the form, *TBI Support Group: Finding a Meeting Location*, which you may find helpful during the process of selecting your location.

## TBI Support Group FINDING A LOCATION

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

*(Modified from text printed with permission by The National Parkinson Foundation)*

## Publicizing Your Support Group

One of the most important steps in starting a group is getting the word out to those who may be interested. Details on how to create and distribute flyers is included in this section. You can also use this section to find out ways to contact newspapers, radio stations, TV stations, and/or use the internet to publicize your group. The more sources you use to publicize information, the more likely you are to get people to attend your group.

Any time you are publicizing the group, make sure you include the answers to these questions:

- **What** is the purpose of the group?
- **Who** is the contact person for this group? Who is invited?
- **Where** is the group held? Include the name of the meeting location, the address, and nearby major cross-streets.
- **When** is the meeting? Include the date, as well as the start and end time.

Publicity is hard work! Don't be discouraged if you do not get a response from everyone you contact. People in the media are busy and cannot always get back to you right away. If you don't get a response from a phone call or email a week after your first attempt at communication, feel free to try once or twice more. If you still get no response, it is time to look for a new contact.

Your first attempt at publicity should be to contact your state Brain Injury Association or your state Aging & Disability Services Administration if you have not done so already. Notify them of your plans to form a new support group and provide them with the information you have about your group. Ask them to send information to their contacts in the area. Request that your group information be included in their next newsletter and placed on their website. Offer to write an article for their newsletter that describes your group.

Here are some specific suggestions to help market and advertise your support group. These are ideas to get you started. As a facilitator, you do not have to follow all of these suggestions. Pick the options that you are comfortable with and that you have time to do.

**Create flyers.** One way to publicize your group is to create and post or hand out flyers to local organizations and businesses. Design a flyer that includes all the information about your group. Keep it simple and not too overwhelming for someone with a TBI to read. *A sample flyer can be seen on the next page.*

It can also be helpful to notify professionals who may be able to refer people with TBI to your group. Flyers should be distributed to places where people with TBI may visit, including:

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

You can also ask community centers, hospitals, religious institutions, or civic organizations to include information in their bulletin or newsletter if they have one.



TBI Support Group  
**SAMPLE FLYER**

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

# Traumatic Brain Injury Support Group

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

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

**When:** The first Monday of each month  
7-8:30 pm

Questions? Call Jane Doe at (555) 555-1212  
or email [jane@gmail.com](mailto:jane@gmail.com)

Hope to see you there!

**Publicize on the internet.** Websites are a great way to reach potential members. You can use websites specific to people with TBI or open to everyone. Try these tips to post information about your group:

- **Go to [www.craigslist.com](http://www.craigslist.com).** Go to your city's homepage and put up a listing under the "community" heading. Post an advertisement under either "groups" or "activities." If you are not sure how to post an advertisement to the website, ask a family member or friend for help.
- **Go to the TBI Survivors Network social networking site at <http://tbisurvivorsnetwork.ning.com/groups>.** Under "groups," you can add the information about your group to attract participants.
- **Search for online community calendars in your area.** Many newspapers, magazines, chambers of commerce, and other media outlets have online community calendars. Post information about your group.
- **Use social networking sites.** If you are involved in sites like Facebook or Twitter or if you have your own website or blog, use these personal resources. Post information about your group to promote it to your friends and other people who follow your news.

*Refer to page 29 for how to create a web presence for your group.*

**Post to community calendars.** Many newspapers have a community calendar section where you can submit information. Pick up your local newspaper and check to see if there is an email or mailing address for the community calendar. If you do not find contact information, go to the newspaper's website and find the email or mailing address for the community calendar. Email a blurb about your upcoming group meeting. If you do not have access to email, call the newspaper. They can help you through the process of submitting information about your group.

**Create a press release.** A press release is a way to provide information to local newspapers. Submit press releases by email or regular mail to newspapers in your area. Look in the newspaper or on the newspaper's website to find a contact person to receive the press release. Submit your release to daily, weekly, and/or monthly newspapers in your area. *Refer to the next page for how to create a press release.*

# TBI Support Group PRESS RELEASE FORMAT

*Use this format for your press release. However, you will need to type your own so the information for your group is correct.*

Contact: (Insert your name here)                      FOR IMMEDIATE RELEASE  
Tel: (Insert your phone number here)                      (Insert the date here)  
Email: (Insert your email address here)

NEW TBI SUPPORT GROUP STARTING (*title is in all capital letters*)

Your city and state, plus the date are inserted here first. The body of the press release follows. It usually answers the questions: who, what, when, where, and why. Include all the relevant information about your group: when the group is starting, where it is meeting, who is invited to attend, and what the meeting is about.

Add in information about brain injury in general. This could be a statistic about the number of people with TBI or the life changes one may experience after TBI. You could include your reasoning for starting a support group in this area.

It is nice to include a quote in the press release. This may be from someone at your state Brain Injury Association or an expert on brain injury. It could be something about the importance of support groups for people with TBI. If you don't have a quote, you could end by mentioning the purpose of the group and how you see it being helpful for the people who attend.

###

*(the three number signs above symbolize the end of a press release)*

If you would like more information about this topic, or to schedule an interview with *insert your name here*, please call *insert your phone number* or email *insert your email*.

**Write a public service announcement.** Many TV and radio stations make free announcements for non-profit groups to promote their events or activities. Go to local radio and TV websites to see if they have a form to fill out. If there is no form to submit, send a copy of your press release by regular mail or email to the station. Ask them to make an announcement about your group on the air.

**Ask for a feature article or news story.**

- **Contact** the editor of your local paper or a reporter from a radio or TV station by phone or email.
- **Explain** that you are starting a new support group for people with TBI and why this group is important.
- **Ask** them to write an article or produce a story about TBI that includes the information about your support group.
- **Include facts** about brain injury and how many people it affects.
- **Add in a human interest element** by telling a personal story of someone with a TBI. Get permission from the person with TBI before telling their story.

**Contact local government representatives.** While this might not help you recruit new members, it is a valuable way to spread the word about what you are doing. By networking with your representative, you are increasing his or her awareness about TBI. This will serve you well later if you get involved in governmental advocacy and need the support of your local representatives.

To learn who your government officials are, go to your state's government website. There will be a page where you can find your representative by putting in your zip code or address. Once you find contact information for your representatives, notify them in writing of your new support group. Follow up with a visit to their local offices. Receive permission to leave brochures or flyers about your group and other TBI resources.

## **Key Points to Remember:**

- Every group is different. You cannot predict how many people will respond to your publicity efforts and attend the first meeting. Do not be disappointed if your first meeting is small. As long as you and one or two other people are interested, you have the basis for building a support group. Many existing groups started with three or less participants and have grown into large groups.
- Once your group starts, the publicity does not end. There will be times when you will still need to contact the media. Sending out a press release when you have a speaker coming to the group is a good idea. If attendance to your group drops, you may need to renew your publicity efforts to attract new members.
- It is important to maintain good relationships with your media contacts. Ask your members if they are comfortable inviting a person from the media to attend one of the meetings. This way, the media can learn more about your group and about TBI. This may lead to a human interest story and even more attention for your group.

## Conducting the First Meeting

The first meeting can be intimidating. You may not know how many people will come or what to expect. It can take a few meetings to get comfortable and to build up membership. Relax. Keep the agenda simple. Be prepared and confident in what you have planned.

**Gather any materials.** These could include:

- A sign to direct participants to the meeting room. This could be taped to the front door or at the front desk. You can also arrange for someone to be at the entrance to the building to greet people and direct them to the meeting room.
- Name tags. These could be stick on labels purchased from an office supply store.
- Pens or markers for people to write their names on nametags.
- Handout of the agenda for each participant. *Refer to page 40 for a sample agenda handout.*
- Sign-in sheets. *Refer to page 38 for a sample sign-in sheet.*
- Refreshments. Purchase enough juice and cookies or crackers for about 10 people for the first meeting (unless you know more will be coming). Set out the refreshments at the beginning of the meeting while people sign in, during the break, or at the end of the meeting while people are socializing.

**Arrive early.** When you get to the meeting location, arrange the room and set up materials. If possible, arrange chairs in a circle to encourage group participation.

**Greet each member.** Welcome people as they arrive and thank them for coming. Point out the name tags and sign-in sheet.

**Begin the meeting.** Ask everyone to take a seat. Request that everyone turn off their cell phones or put them on vibrate or silent.

**Introduce yourself as the facilitator.** Explain your purpose as the group facilitator. Tell the group how you are there to help plan meetings, guide discussions, and keep the group on task. Be open and honest about what made you decide to start this group. Share your hopes for how you see the group being helpful and meaningful.

**Introduce the group members.** Ask everyone to share their name and what brings them to this meeting. You may also ask what they hope to get out of the support group. Do not pressure anyone to share if they are not comfortable doing so. Ask participants to be brief so everyone has a chance to share. Be prepared to redirect if someone takes too much time.

**Discuss confidentiality.** Explain that what people share in the group should not get repeated to anyone outside of the group. Tell the group that the sign-in sheet is to keep a record of who attends each meeting. As a facilitator, you will not share their personal information without permission.

**Establish ground rules.** Suggest basic rules to help meetings run smoothly. These can be simple ideas like starting meetings on time, respecting other members, keeping comments brief, and listening without interrupting. Take a vote as a group to decide on the rules your group wants to follow. *See page 52 for more information on how to set up and use ground rules.*

**Lead a simple activity.** Check out the *Support Group Activity Guide* for icebreaker activities. Choose a short (5-10 minutes) simple exercise to lead. This is a good chance to learn something about the members of the group. It can help people feel more comfortable and more willing to share with each other.

**Take a 10 minute break.** If you are facilitating a 2 hour meeting, allow time for people to stretch their legs and use the restroom.

**Brainstorm ideas for future meetings.** It is important to hear from group members about what is important to them. What do the members want out of future meetings? Are they more interested in sharing personal experiences or having speakers? Do they want to have a social component to the group? What needs do they hope to meet with these meetings? Write down everyone's suggestions. Make every member feel that their suggestions are valued. *Use the Support Group Activity Guide for activities on different topics at later meetings.*

**Decide on the main activity for the next meeting.** Gather ideas about what group members would like to focus on for the second meeting.

**Thank the participants for coming and close the meeting.** Share your contact information with members. Remind the group of the date, time, and location for the next meeting and to add their contact information to the sign-in sheet. Let members know that you will contact them via e-mail, mail, or phone to remind them of the next meeting. Now would be a good time to ask for a volunteer to help with sending out reminder information for future meetings. Make yourself available for questions.

**Allow time for socialization.** Designate 10-15 minutes at the end of the time for members to socialize. Knowing there will be time at the end of the meeting to chat may help members stay on track during the meeting.

Other items that may be addressed and voted on at the first meeting:

- How much time would people like at the end of the meeting to socialize with other members?
- Do members want refreshments at every meeting? The group should discuss whether refreshments will be too messy or distracting. Also, should the facilitator provide the refreshments or do the members want to rotate bringing them each meeting. How will the refreshments be paid for?
- Are caregivers or family members allowed at meetings?



## Sample Structured Meeting

As the group gets more comfortable with each other, the way meetings are conducted may change. The facilitator may continue to organize and manage each meeting, or group members may take on more responsibilities. Members might rotate the facilitation each meeting or may be assigned to a specific role like greeter or set-up person.

Plan a structure for each meeting. This is helpful even if the meeting is more informal. Structure provides a chance for everyone to be heard and for important issues to be addressed. It also helps the group feel a sense of continuity and routine. Here is an example of a structured meeting. Adapt it as needed so that it fits your group.

**Welcome.** Welcome everyone to the group and introduce newcomers. Remind everyone of the purpose of the group. Review the ground rules. Explain the importance of confidentiality.

**Call for a check-in.** Newcomers can state their names and the reason why they have come. Other members can give a brief statement (1-2 minutes) about how they have been doing since the last meeting. To keep the group running on time, you may use an egg timer to cue people when their time is up.

**Begin the main activity.** The majority of the meeting can be spent in a number of ways.

- If there is a speaker, there will be a presentation followed by a question and answer period.
- If it is a meeting on a particular topic, the facilitator might lead an activity from the *Support Group Activity Guide*, or use discussion questions to get people talking.
- If it is an open meeting, the facilitator might ask the group if there are any issues or problems that someone would like to bring up.

The facilitator will guide the discussion, allowing everyone time to speak and be heard. Supportive information or resources may be shared among the group. *See the Support Group Activity Guide for resources and ideas on how to plan specific meetings.*

**End the meeting.** Before closing, call for volunteers to take on specific responsibilities for the next meeting. See below for ideas on types of roles that can be assigned. This can help the facilitator from feeling overwhelmed. Thank everyone for their participation. Remind them of the date, time, and location of the next meeting.

**Socialization.** Some groups may choose to end the formal part of the meeting, but stay at the location for another 15-30 minutes or so to ask questions and socialize. This can be a time for refreshments and catching up with other members.

**Roles and responsibilities.** Some groups may choose to assign roles and responsibilities for members. This allows members to be involved and feel some ownership of the group. These are not mandatory responsibilities since some groups are not large enough for this to work.

Roles and responsibilities that may be assigned for each meeting include:

- **Snack and/or beverage provider:** Purchase, bring, and/or set up snacks and drinks.
- **Set-up and take-down person:** Get the room set-up before the meeting starts and return the room to its original state at the end of the meeting.
- **Greeter:** Welcome members and ask them to fill out the sign-in sheet.

Roles that a member may hold for a longer term (6-12 months) include:

- **Secretary:** Take notes during the group session. Remind this person that because of confidentiality, they cannot use anyone's names in the notes. Keep the notes in a secure location between meetings.
- **Librarian:** Store and track books and other reference materials on loan to members.
- **Public relations person:** Collect relevant stories/articles from newspapers, magazines, and the internet and share these with the group. May also keep the local media up-to-date on group meetings, activities, and scheduled speakers.
- **Treasurer:** Pass donation jar around and keep track of donations and expenses. This person needs to be very organized.
- **Communication chair:** Make reminder calls/emails before each meeting.

- **Substitute facilitator:** Step in to lead the meeting if the facilitator is ill or cannot lead the group.

*See page 40 for an example of a sample agenda that can be handed out to group members at the meeting.*

# Administration

## Creating a Web Presence

**Create a website.** If you, someone in your group, or a group member know someone who has web development experience, a website is a great tool for your group. This can be a place to post meeting agendas, remind members about advocacy efforts, share pictures of social activities, post group updates, or to recruit new members.

**Create a blog.** If no one in your group has web development experience, creating a blog is an easier process. Someone with moderate computer skills can set up and maintain a blog. This is a good option if you wish to keep information private. You can set the privacy settings to allow only your group members access to the content. You can also have members submit entries or stories so that everyone can contribute to the blog.

Two websites where you can create your own blog for free are:

[www.blogger.com](http://www.blogger.com)  
[www.wordpress.com](http://www.wordpress.com)

**Use a group network site or online forum.** This is a place for your group to send information to all the other members. Members of your group can communicate with each other between meetings. They can exchange ideas, discuss issues, send reminders for events or meetings, or ask questions. Any group member can post to an online forum or group site.

Go to [www.groups.yahoo.com](http://www.groups.yahoo.com) for one place to create a group forum. At [www.facebook.com](http://www.facebook.com), you can create a group for your TBI support group.

**Join a social network site or chat room.** Online social networks or TBI chat rooms are another great way for people to connect. Provide your members information about websites that allow your members to connect with others outside of your group. Some social network sites for people with TBI include:

<http://tbisurvivorsnetwork.ning.com>  
[www.braininjurychat.com](http://www.braininjurychat.com)

**Be creative!** It is important for people with TBI to feel connected with others. Creating a web presence for your group or allowing opportunities to connect with other TBI survivors online can help everyone feel more united.

## Safeguards

A successful support group creates a safe environment for its members. The following tips are suggestions to establish a supportive atmosphere.

**Emphasize confidentiality.** Remind the group members that each meeting is a chance for people to share honestly about themselves. Discussions should not be shared outside of the group.

**Refer for counseling.** Facilitators and members should not provide counseling services to each other. If a member requires professional support or referrals for counseling, encourage the member to call their state TBI Helpline. The member may also contact the Brain Injury Association of America by phone (703) 761-0750 or on their website:  
<http://www.biausa.org/>

**Screen speakers.** When inviting a speaker, make sure that the person will be a good fit with the support group members. You want to avoid speakers who have their own agenda and are speaking to solicit for their personal gain. Ask basic questions before signing them up for a meeting. For example, “What are you planning to talk about?” “What experience have you had with individuals with Traumatic Brain Injury?” Some topics that are presented may be controversial. Tell your group that the views of the speaker may not reflect every individual’s views. *See page 45 for how to choose an appropriate guest speaker.*

**Consider liability insurance.** This can be an additional precaution in the case of an emergency. While some meeting locations may cover your group should any incidents occur, it is a good idea to ask your local Brain Injury Association for more information if you would like to secure insurance.

# How to Find a Sponsor

## What is a sponsor?

A sponsor is a company that donates material or money to help support your group.

## How can a sponsor help?

Even a small local support group needs some funds. Stamps, copying handouts, and refreshments can add up. Some groups use a donation jar and clearly state that members only need to donate if they are able. While donations are helpful, they may not provide enough money to cover all the costs.

Finding a sponsor for the group may be the answer. Examples of likely sponsors include the state Brain Injury Association, non-profit organizations, hospitals, health organizations, churches, grocery stores, or businesses. You can ask for cash donations or services like copying or printing.

## How do you find a sponsor?

**Make a list of the items your group needs.** Then match each item to a list of possible businesses and organizations within your community you can contact for help.

**Approach each business or organization.** Write up a description of your support group and the group's goals and needs. This way, the sponsor has a clear idea of what is needed.

**Get the specifics.** Find out if the sponsor is willing to continue this donation or if it is a onetime offer. Find out if they want you to advertise on your website or agenda for them in return. Based on those factors, decide if you want to use that sponsor.

**Decide to use the sponsor.** Collect the donation and use it as needed, or go to that business to take care of specific needs, such as using a copy machine.



**Send the sponsor(s) a thank you letter.** This lets the sponsor know that you appreciate the services provided. It may also increase the chance that the sponsor will donate in the future.

Examples of sponsors and how they can help:

**State Brain Injury Associations** have a lot of information and resources. This may include monetary help or suggestions for where to find assistance in your local area.

**Hospitals and community organizations** may donate written material like books or brochures.

**Churches or businesses** may offer the use of copy machines and help with mailing support group material.

**Grocery stores** may donate refreshments for meetings.

**Businesses** may sponsor special outings or events that the group can attend.

## Finances

Having one person, such as a treasurer, in charge of the money may not be needed in the early stages of forming a group. As the group grows, it may be something to consider. The treasurer can keep track of all the financial changes and let the group facilitator know the balance of the finances. Designating or voting on a support group member to be in charge of finances is one way to stay on top of the finances.

It is best to have a checking account to handle support group money. Open an account if there is not an existing one for this support group. State Brain Injury Associations can give you information about which bank to use and the exact steps needed to open an account.

It is important to keep an up-to-date financial record.

- Having a checking account provides a secure place to look at:
  - How much money has come in
  - how much money has gone out
  - where the money went
- As the group gets cash donations, put it into the bank account.
  - Keep a record of service donations.

## Expense and Income Sources

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

### Expenses:

- Group Meeting Costs:
  - Food/beverages
  - Room rental
- Ongoing Material Costs:
  - Paper
  - Copying
  - Postage
- Ongoing Administrative Costs:
  - Advertising
  - Insurance/liability
- Other Possible Costs:
  - Resources: books, DVDs, pamphlets/brochures
  - Cleaning supplies
  - Field trips or social activities
  - Fees for guest speakers
  - Organization dues
  - Support group facilitator stipend
  - Phone service

### Incomes:

- Grants/federal support
- Donations from support group members and sponsors
- Fundraisers

## Record Keeping

The following pages are samples of forms that will help you to stay organized. Make as many copies as you need. Store them in a notebook with dividers between each section for easy access.

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

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

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

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

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

# TBI Support Group CONTACT LOG

Facilitator: _____	Date: _____
<p>Name: _____</p> <p>Address: _____</p> <p>_____</p> <p>City/State: _____</p> <p>Zip: _____</p> <p>Email: _____</p> <p>Participation level interest:  <input type="checkbox"/> Member <input type="checkbox"/> Organizer <input type="checkbox"/> Other</p> <p>Other Information: _____</p> <p>_____</p> <p>_____</p>	<p>Name: _____</p> <p>Address: _____</p> <p>_____</p> <p>City/State: _____</p> <p>Zip: _____</p> <p>Email: _____</p> <p>Participation level interest:  <input type="checkbox"/> Member <input type="checkbox"/> Organizer <input type="checkbox"/> Other</p> <p>Other Information: _____</p> <p>_____</p> <p>_____</p>
<p>Name: _____</p> <p>Address: _____</p> <p>_____</p> <p>City/State: _____</p> <p>Zip: _____</p> <p>Email: _____</p> <p>Participation level interest:  <input type="checkbox"/> Member <input type="checkbox"/> Organizer <input type="checkbox"/> Other</p> <p>Other Information: _____</p> <p>_____</p> <p>_____</p>	<p>Name: _____</p> <p>Address: _____</p> <p>_____</p> <p>City/State: _____</p> <p>Zip: _____</p> <p>Email: _____</p> <p>Participation level interest:  <input type="checkbox"/> Member <input type="checkbox"/> Organizer <input type="checkbox"/> Other</p> <p>Other Information: _____</p> <p>_____</p> <p>_____</p>

# TBI Support Group SIGN IN SHEET

Facilitator:

Date:

Name	Address	State	Zip	Phone	Email

# TBI Support Group MEETING PREPARATION CHECKLIST

Facilitator: \_\_\_\_\_

Date: \_\_\_\_\_

## Two Weeks before Meeting:

- Media notified
- Reminder cards mailed
- Speaker confirmed (if applicable)

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

## Week of Meeting:

- Reminder phone calls to members
- Refreshments arranged
- Print handouts and other program materials

## Day of Meeting:

- Name tags
- Pens
- Paper
- Agenda
- Directional signs for meeting location
- Sign in sheets
- Handouts and other program materials
- Ground Rules (if not posted on Agenda)

## Notes:


# TBI Support Group **SAMPLE AGENDA**

Facilitator:	Date:
--------------	-------

<b>Welcome and Introductions</b> <i>(Remind everyone the purpose of the group, importance of confidentiality, review ground rules)</i>	Facilitator	20 minutes
<b>Topic of the evening</b> <i>(Such as “What is the best advice a doctor has given you?” or “What makes you happy?” etc)</i>	Group	30 minutes
<b>Break</b>	Group	10 minutes
<b>Speaker of the night</b> <i>(with discussion afterwards )</i>	Group	30 minutes
<b>Closing</b> <i>(Agree on whatever agenda items need to be addressed and who will be taking specific responsibilities for the next meeting)</i>	Facilitator	30 minutes

**Ground Rules**

*(This is a place to write the agreed upon ground rules of the group)*

**Additional Information**

*(This is a great place to put notices, reminders, meeting guidelines, community events, recognitions etc.)*



# TBI Support Group NEW MEMBER QUESTIONNAIRE

Facilitator:

Date:

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

Phone number: (optional) \_\_\_\_\_

What are the most frustrating things that you are currently dealing with?

\_\_\_\_\_

Do you feel that services for individuals with brain injury are adequate?

Yes       No      please explain why:

\_\_\_\_\_

Are you and your family getting the services you need?

Yes       No      If no, what services do you need that you have not been able to find?

\_\_\_\_\_

What do you hope to gain from participating in a support group?

\_\_\_\_\_

What type of speakers or other information would most benefit you?

\_\_\_\_\_

Do you feel that the time and location of the meeting is convenient?

Yes       No      If no, how often, what time, and where would you like the group to meet?

\_\_\_\_\_

Would you be interested in helping lead the group or helping with future meetings and events?

Yes       No      If yes, how would you like to help?

\_\_\_\_\_

## Fundraising

While the main purpose of the group is support, fundraising can help sustain a group. Some groups may automatically receive funding from partner organizations. Other groups may want to raise money through fundraisers or grant writing. This is not a requirement to run a successful group, but an option if the facilitator and group members have the time and energy. If you decide to try fundraising, keep it simple, low-cost, and fun. Fundraising can also be an opportunity to educate the public about brain injury.

Some support groups receive state, federal, or private funding. Contact your state Brain Injury Association or Department of Social and Health Services (DSHS) to learn if there are funding opportunities in your area. There may be an application process to show that your group meets certain standards. You may not be able to rely on getting this money every year. Doing additional fundraising can help sustain your group.

Ideas for fundraising include:

- Write or visit local businesses and civic organizations to ask for donations.
- Host a special event. Examples include a walk-a-thon, bake sale, rummage sale, or community dinner.
- Design and sell t-shirts, buttons, or bumper stickers to help raise awareness about TBI.
- Partner with a development professional (a grant writer) to talk about possible grant funding.
- As a group, agree to pass around a “dues and donations” jar at each meeting. It is an optional way for members to help with costs of the group if they feel comfortable donating.

Once your group receives additional money to help run your support group, you can use it to:

- Pay for parking if that is a cost at the meeting location
- Give a stipend to the group facilitator
- Buy refreshments for meetings
- Copy handouts
- Purchase any necessary materials
- Pay for speakers
- Organize social activities and outings
- Pay for meeting space

*See page 34 for more information on finances.*

# **Sustaining a Support Group**

## Finding Guest Speakers

Having a guest speaker can bring in additional experiences and perspectives. A guest speaker may be a professional who works with people who have a TBI. The speaker may also be someone who does not work with people who have a TBI, such as an attorney or artist.

When finding a guest speaker, make sure his or her information will be helpful for your group members. The speaker should NOT be there to sell a product or promote a treatment. You may be approached by someone who wishes to speak to your group. A group may express a desire to have someone talk to the group on a particular subject. As facilitator, it is your responsibility to choose an appropriate speaker or assign a group member to the task. Both your support group and the chosen speaker should be given a copy of your Speaker Disclaimer prior to the presentation.

Here is a sample Support Group Speakers Disclaimer. Make appropriate changes for your group.

“This support group and (include your sponsor’s name here, if applicable) does not specifically endorse any of the speakers that present. The sponsor does not make any warranty or assume legal liability or responsibility for the accuracy of any information presented. The information does not replace recommendations and opinions of licensed health care professionals. No members of the sponsor’s staff, Board of Directors, volunteers, or others connected to the sponsor takes any responsibility for some other person or entity using or adopting any of the information presented by a speaker at a support group. Also, no information on the sponsor’s website should be construed as attempting to offer, offering, or rendering a medical or health care opinion or otherwise engaging in the practice of health care.”

Below are ways to find and prepare a guest speaker for your group.

**Decide who to ask.** Here are ideas.

- Medical Professionals
  - Neurologist
  - Psychologist
  - Nurse specialist
  - Physical therapist
  - Occupational therapist
  - Speech pathologist
  - Recreation therapist
  - Pharmacist
  - Dietician
  - Exercise physiologist
- Community Health Professionals
  - Social worker
  - Representative from county office on aging
  - Adult day care or nursing home staff
  - Hospital or nursing home chaplain
- Community Arts and Leisure Professionals
  - Speaker from a local museum or historical site
  - Dancing or music instructor
  - A local artist
  - Computer teacher willing to teach adaptive computer techniques
- Community Professionals
  - Attorney
  - Owner of a local medical equipment company
- One of your own members who has had a recent adventure, publication, art show, or has traveled

**Contact the speaker** and find out if they are available for your meeting time. The difference between a well-prepared presentation and a presentation that misses the mark is often due to the communication between the speaker and the person who invited the speaker. The following list has been developed to assist you in communicating your expectations to a speaker. Use the template on the next page as a check list to complete each step. *(The list is adapted with permission from the International Essential Tremor Foundation.)*

# TBI Support Group FINDING A GUEST SPEAKER CHECKLIST

Speaker: \_\_\_\_\_

Date: \_\_\_\_\_

**Topic:** \_\_\_\_\_

**One month ahead:** Call or email the potential speaker

**Tell them:**  Who you are.

Why you want them to come and speak.

Topics that may be helpful for TBI survivors.

How long they have to present.

**Ask:**  Is there a charge for the presentation? \_\_\_\_\_

If so, how much? \_\_\_\_\_

Email address: \_\_\_\_\_

Phone number: \_\_\_\_\_

Mailing address: \_\_\_\_\_

\_\_\_\_\_

Background: \_\_\_\_\_

\_\_\_\_\_

**Confirm:**  Time: \_\_\_\_\_

Date: \_\_\_\_\_

Location: \_\_\_\_\_

Topic of presentation: \_\_\_\_\_

Length of presentation: \_\_\_\_\_

# TBI Support Group FINDING A GUEST SPEAKER CHECKLIST (2)

Speaker:

Date:

## **Two weeks before the meeting:**

- Call or email the speaker a reminder note  
("We're looking forward to seeing you on...")
- Reconfirm the time and format  
(For example, a 30-minute talk with 15 minutes for questions and answers).
- Ask the speaker to bring their own video equipment, slide projector, flip chart, or other visual material, if your location does not provide these items.
- Give the speaker good directions and a telephone number to call in case of any last minute problems. Ask the speaker for a cell phone number.

**Speaker's cell phone number:** \_\_\_\_\_

## **Optional steps to prepare:**

- Can we take photos and/or video record the presentation?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_



## TBI Support Group FINDING A GUEST SPEAKER CHECKLIST (3)

Speaker:

Date:

### **At the meeting:**

- Write the speaker's name on the board or flip chart in large letters.
- Introduce the speaker.
- Encourage the speaker to use a microphone, if available.
- If time has been allotted for questions and answers, let everyone know what the time limit is and stick to it.

### **Question and answer period:**

- Make sure that each person who would like to ask a question has an opportunity.
- Offer to restate questions for group members.

### **Closing the meeting:**

- Keep track of time.
- Provide a five minute warning before the time is up.
- Provide a warm "thank you" on behalf of the group at the end of the presentation.
- Show your appreciation by clapping at the end of the presentation.
- If the speaker needs to leave at a certain time, respect that. You may send members' remaining questions to the presenter by email.
- Ask the speaker if he or she would like to be on your mailing list.

### **After the meeting:**

- Send a "thank you" card within a week of his or her visit.

## **BIAWA Library**

In planning your groups or when interacting with members, you may want more information about topics related to brain injury. These may include subjects like employment, family issues, or stress. Know that you do not have to search far for articles and books. Check with your local Brain Injury Association or the Brain Injury Association of America for details on how to access information.

The Brain Injury Association of Washington (BIAWA) has an extensive online library. Go to <http://www.biawa.org/library.htm> for free articles available to download in Microsoft Word documents and PowerPoint presentations.

Article topics include:

- Behavior management
- Children
- Cognition
- Coma
- Driving
- Education
- Employment
- Epilepsy
- Family issues
- First person accounts
- Generic brain injury information
- Guardianship
- Legal issues
- Minor head injury
- Neuropsychology
- Rehabilitation
- Social adjustment
- Stress
- Substance abuse

## **Facilitator Trainings**

Beyond information found in a manual, facilitator trainings give you a place to pick up more tools for your toolkit. You can learn icebreakers and group exercises, practice facilitation and intervention methods, share the challenges you face, and brainstorm solutions with other facilitators.

Consider this a Build-Your-Own section of the manual where you can add slides, notes, and flyers from trainings. To get you started, here are samples of past training materials compiled by the Brain Injury Association of Washington.

## Behavior Guidelines

Sometimes even the most well-connected group and well-prepared facilitator have meetings where a member dominates the conversation or someone has an emotional outburst. Relax. Conflicts occur. The purpose of this section is to prepare you for handling disruptive behavior that may come up when running a TBI support group. Attend trainings to learn more about difficult behaviors and to practice specific management techniques.

**Consider the environment.** Remember that members recovering from brain injury may be sensitive to bright lights, noise, and activity. Before each group, check the meeting room and adjust lighting or seating to decrease distractions.

**Establish ground rules.** Guidelines establishing expected behavior for group members should be formed in the first few meetings. The guidelines should be decided on by the entire group to ensure acceptance and compliance by the group. Network with other established support groups to assist in developing ground rules. Think about what will and will not work for your group. For example, establishing a guideline that only one person can speak at a time is reasonable, however, asking members to never stray from the discussion topic is not.

- **Involve the group.** As mentioned in the section *Conducting the First Meeting* (page 22), keep the ground rules basic. Setting ground rules can be done in a casual brain-storming session during the first meeting. The group can add ideas as they develop. The important point is to make sure that the members have ownership of the rules they will follow.
- **Agreements, not punishments.** The support group is a place where people with brain injuries are invited to practice appropriate social and communication skills. Remind members that the guidelines are agreements to help everyone get the most out of the meetings, and are not meant as reprimands.

- **Examples.** Here are two examples of guidelines established by current support groups. These guidelines are reviewed at each meeting. They are posted on the wall of the meeting room and/or written out on that session's agenda.

### **Support Group Agreements**

*(From the Tacoma, WA Brain Injury Support Group)*

- One person speaks at a time.
- Accept and affirm each other. Differences of opinion are ok.
- What is said here, stays here.
- We are all equal. Respect other member's differences.
- Offer support.

### **Support Group Guidelines**

*(From the Cherry Hill Brain Injury Support Group in Seattle, WA)*

- We ask that members strive to arrive on time. If you arrive late, please enter quietly and try not to disrupt the group conversation or activity.
- We expect every person attending this group to be very respectful and positive to other members.
- You only need to share with others what you are comfortable sharing. It is okay to "pass" when asked to speak.
- We give equal time for everyone to speak, so before speaking twice, make sure everyone else has had the chance to speak once.
- When speaking try to use "I" statements, talk about your own experience.
- Refrain from giving advice to another group member, unless that person specifically requests it.
- Always make sure to keep the things that you hear in this group confidential.

**Post the ground rules.** Once you have established the ground rules, have them posted on a display board, flip chart, or on the agenda at each meeting. You can also choose to have laminated copies available for members to read out-loud at the start of each session. This will be helpful for newcomers who join after the group is formed and to remind regular members of the expectations.

**Directly enforce when ground rules are not followed.** Directly address the member who is not following a ground rule at the moment it happens. This does not mean that it has to be a long conversation or even cause embarrassment. Treat the member as an adult and remind everyone of the agreements. Here are two examples of how to reinforce the rules:

- **Side conversation:** If someone is sharing and two people are having another side conversation, you can stop the speaker and say, “Adia and Brian, remember that the ground rules say that only one person will speak at a time.”
- **Verbally attacking:** If one person is verbally insulting another person, immediately stop them by physically holding up your hand. Ask them to redirect their behavior. “Carlos, in the ground rules, we agreed to respect and listen without judging others. Calling another member lazy is not respectful. Carlos, please say something positive or constructive if you would like to add to the conversation.”

**Redirect rather than criticize.** This is especially useful if a member is talking for a long time or getting off-topic. For example, say, “Thank you, Larry, for sharing. That sounds interesting...let’s talk about it more after group.” The member will feel heard and the conversation can get back on track.

**Follow up.** If a behavior is addressed in the group, the facilitator may want to follow-up individually with the member after the meeting to make sure they understand what happened.

**Limit attendance.** If a member continually cannot follow the group ground rules, you can ask him or her to take a break from the group until he or she can come back and follow the group agreements. Be respectful during this conversation. You may suggest the person attend another type of group before returning to the TBI support group. Groups specifically for anger management or post traumatic stress disorders may be more appropriate for some members.

**Have a plan for escalated behaviors.** If you have tried other methods and the participant's behavior becomes aggressive or violent towards another member, get additional support. To prepare for this:

- Find out if there is security or managerial staff available for emergency support at the building and how you can quickly contact them. If you expect there will be a conflict, you can also ask your advisor to attend the meeting.
- Identify a backup support person in the group who will contact the building security or staff.
- If an incident occurs, contact your advisor and building security as soon as possible.

## Getting Your Group Involved in the Community

Many groups enjoy planning additional meetings or activities outside of their regularly scheduled group. This gives members a chance to socialize, volunteer, and/or advocate for issues related to TBI. *See page XX of the Support Group Activity Guide for more information on planning events.* Ideas for getting involved with the community include:

### Volunteering

- Clean up a park or neighborhood
- Ask a staff member at your meeting location if that organization needs any volunteer help
- Contact a nonprofit brain injury organization to see if they need assistance with an upcoming event, office clean-up, or mass mailing
- Organize a food drive for a local food bank
- Prepare and serve meals at a local soup kitchen
- Contact the volunteer coordinator at a nearby non-profit. Try calling a senior center, animal shelter, or environmental organization to see what opportunities they have for volunteering

### Social Activities

- Organize a picnic or potluck for members and their families
- Plan a joint meeting with another support group
- Meet at a local restaurant for lunch or dinner
- Hold a holiday celebration or a theme party
- Attend a movie or play
- Go bowling
- Plan a hiking or camping trip

### Advocacy

- Develop a TBI informational display for the local library during Brain Injury Awareness Month in March
- Write letters or emails to local legislators about policies and bills affecting people with TBI
- Invite a state representative or senator to hold a question/answer session at a future meeting
- Encourage members to participate in state legislative days or to visit their local representatives



## Networking

Networking is being part of a support system that shares services and information among people and groups that have a common interest. Networking has multiple benefits. Networking allows for your group members to see other groups, how they run, and what material they cover. It will prepare members for a better understanding of the many unique needs of survivors and their families.

For the facilitator, networking or interacting with other support groups and facilitators is a way to find new topic ideas, assess group dynamics, and provide ideas to increase group participation.

### What does networking look like?

You and your group members can network in different ways. Members or facilitators can get together with other support groups in the area to find out what other groups are like. Another option is online networking. That way, members have access to other peoples' support throughout the world. Members can also network among themselves and develop their own support network.

Contact other advocacy groups. Look for groups with other disabilities such as mental health, epilepsy, or spinal cord injuries. There are many groups that have a blend of different disabilities.

To help others find your group and network with you, announce your support group (*see page 17 for the Sample Flyer template*) in newsletters in your community.

### How to find other groups

**Ask your group members.** Survivors often attend more than one support group. Ask members to share information about other support groups they attend. Encourage members to visit other support groups.

**Ask your state Brain Injury Association.** There are many support groups associated with the Brain Injury Association. Area groups may focus on different aspects of support. Some may focus on socializing and others may focus on education. Some groups may be geared toward

caregivers and others for survivors. Consider attending another group that has a different focus than yours. For example, if your group is educationally based, ask a more social group if you can join them for one of their events, like bowling.

**Ask support group leader friends.** You may become friends with other support group leaders. Joining two groups for an evening when a special guest speaker is presenting is a great way to network two groups together.

**Contact local hospitals.** Many hospitals provide support groups for various conditions. If they do not provide support groups, they may know of other hospitals or places that do.

**Contact day treatment centers.** Like hospitals, they may provide a room for a variety of support groups. They may be able to tell you where to find other groups.

## Handling Transitions

Support groups grow and change over time. New members will continue to join and long-time members may leave. Make sure you welcome new members and invite them to share as much or as little as they feel comfortable with. The transitions that might be more challenging to address are when active members and/or group leaders move on.

If you need to take a leave of absence or are unable to continue facilitating the group, contact your local Brain Injury Association for assistance finding a replacement. It is important to tell the group as soon as possible that you will be leaving. It is your choice how much detail you want to give for your reasons. Let the members know what the next steps are, including who will lead the group until a permanent replacement can be found. You may want to ask the group if there is anyone who would like to be considered as your replacement. Make it clear that they may have to go through an application process, a background check, and interview. Allow time for questions.

If a member leaves the group, don't consider it a failure. Each group cannot meet the needs of every group member. This person may find another group that fits his or her needs better. It may also mean that the person has gotten to a place where he or she no longer feels the need to attend a support group. Personal circumstances may also be a reason why the member can no longer participate in the group. There may be a sense of loss among the group members. It is important to allow some time to discuss those feelings in a supportive environment. As much as we value support groups, some people feel that support groups are not for them.

As the facilitator, finding out why the person left may be important. This is especially true in situations where the person was unsatisfied with aspects of the group. Understanding what parts of the group are working and what needs to be improved upon is information worth knowing. This way, you can change aspects of the group if needed. There are different ways to find out why a member left. It is important to get the information directly from that member. This can be done through a phone call or a survey sent by email or mail.

There are also situations where one group may turn into several different groups. If your group members have many perspectives or a variety of roles, those with a common link may gather separately and form another group. For example, those who are caregivers or parents may branch off so they can discuss their own viewpoint. If the group gets too large, a satellite group may develop. If the new group meets at a different time, people may decide to attend both groups.

As a facilitator, it will be important to look for those specialized interests and perspectives among your group. There may not be many support groups already created for these specialized populations like veterans or caregivers. Encourage those members to start a focused group. Provide them with resources to get going.

## Evaluation and Feedback

It is important to get feedback from your group members every 3 to 6 months. This helps you know if the group members are getting what they want out of the meetings. Be aware that you may get a variety of positive and negative feedback. Not all group members have the same expectations. Do not be offended if a group member complains about an aspect of the meetings. Take everyone's feedback into consideration, but understand that you cannot please everyone. Try to make changes as needed that satisfy the group as a whole.

### Three ways to get group feedback:

**Informal check-in.** Take 20 minutes at the end of a meeting to hold a discussion about how the group is doing. Ask members what they like about the group. Ask for suggestions about what to change to improve the group. Ask someone to write the comments down so you can reflect on them and decide how to put them to use.

**Suggestion box.** At every meeting, you can bring a small box or envelope for written suggestions. Members can use a piece of paper to write down any comments about how the group is running or what they would like to change about the group. People are not required to put their names on the paper. This usually makes people more willing to submit ideas.

**Evaluation form.** An evaluation form can be passed out to group members. You can hand it out near the end of the meeting and give members 15 minutes to fill it out. Another option is to pass it out at the end of the meeting and ask for members to return it at the start of the next meeting. This could be used once a year to receive feedback about the group. *Refer to the next page for a sample evaluation form*

If you choose to make any big changes to how the group is structured, be sure to explain the change before implementing it. Tell the group members that this modification is based on their feedback. Groups tend to change and evolve with time. Remind members to be flexible. Thank them for their continued suggestions for improvement.

# TBI Support Group EVALUATION AND FEEDBACK FORM

Facilitator: \_\_\_\_\_

Date: \_\_\_\_\_

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

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

Phone number: (optional) \_\_\_\_\_

What is your favorite thing about the group?

\_\_\_\_\_

What is your least favorite thing about the group?

\_\_\_\_\_

How effective is the facilitator at leading the meetings?

Very effective

Somewhat effective

Not effective

Comments:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How can this support group be improved?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Additional comments, suggestions, questions, or concerns:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Thank you for your feedback!**