

# Ten Insider Tips and Tools



## A Manual

**For Starting or Improving  
a peer-to-peer  
SUPPORT GROUP**

Created by and freely offered by

**John Pistorius of the  
Brain Injury Support Group Alliance  
<http://www.bisga.org>**

**“Successful people are always looking for opportunities to help others. Unsuccessful people are always asking, 'What's in it for me?’”  
-Brian Tracy**

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## Table of Contents

<b>Acknowledgments</b> .....	Page 2
<b>Introduction</b> .....	Page 3
<b>Insider Tip Number One:</b> .....	Page 5
Support Begins with Respectful Language	
<b>Insider Tip Number Two:</b> .....	Page 10
Recognize the Need for Peer Support	
<b>Insider Tip Number Three:</b> .....	Page 12
Plan Your Work	
<b>Insider Tip Number Four:</b> .....	Page 15
Organize Your Tools and Work Your Plan	
<b>Insider Tip Number Five:</b> .....	Page 18
Announce, Publicize, Promote, Broadcast and Publish your Meeting Notice	
<b>Insider Tip Number Six:</b> .....	Page 20
Contact Local Government Representatives	
<b>Insider Tip Number Seven:</b> .....	Page 21
Network with Local Hospitals and Medical Centers	
<b>Insider Tip Number Eight:</b> .....	Page 23
Contact and Network with Schools, School Nurses, and Athletic Directors	
<b>Insider Tip Number Nine:</b> .....	Page 24
Establish a Regular Course of Action	
<b>Insider Tip Number Ten:</b> .....	Page 26
It Starts With You Making Accessibility Real	
<b>Wrap-up</b> .....	Page 27
<b>Resources</b> .....	Page 28

## **Acknowledgments**

I owe a tremendous debt of gratitude to all of the people who pioneered peer-to-peer Support in my hometown of Pittsburgh, Pennsylvania, USA. Without their dedication and persistence, I might never have become involved within this movement.

Many people have unknowingly contributed to the development of this Insider Tips Manual. Some have aided the creation of this manual by encouraging me to follow my heart. Others have helped by expressing the need for leadership training. And still others have shown me that the time has come for Support Group Leaders and would-be leaders to have a reference manual to help them in their leadership role. After all, any peer support group is only as strong as the people who lead it.

This manual is the fruit of years of leadership service, unselfishly devoted by countless individuals. These everyday people did what they could, even when they didn't know what to do. They generously gave of their time and money to insure the continuation of peer support for people who experience brain injury. I dedicate this document to these unsung heroes. They are the real celebrities.

My personal mentors have also assisted me in this work without realizing their influence. Their inspiration for me to work through my personal conflicts has enabled me to do what I knew needed to be done with peer-to-peer Support. This manual would not have been possible otherwise.

My wife and young children have assisted in this endeavor by their love, understanding and devotion to me. They have unsparingly consented to my volunteer efforts. My pursuit of developing and strengthening peer support groups would not have been possible without their acceptance.

I want to acknowledge the readers of these pages. You and your loved ones are the reason I've done this. You will be blessed as you strengthen or develop peer-to-peer Support in your area. The people who experience the benefits of peer support will be forever changed in positive ways that might be unimaginable to you right now. You can rest assured that you are making an undeniable contribution to society and the individuals your group serves.

Andrea Williams deserves a great deal of thanks for helping me understand cognitive accessibility. Her unselfish devotion to overcoming accessibility barriers has been an inspiration to me in my work. It was Andrea who saw my potential and helped me to overcome the obstacles to understanding cognitive accessibility. She is the true Champion of persons with disabilities. Thank you Andrea, without your guidance, I'd have walked away long ago.

While this manual has been designed with brain injury and cognitive impairment concerns as its central theme, much of what is written here can be adapted to be used in the development of any type of peer-to-peer Support Group. Please feel free to adapt this manual to establish peer-to-peer Support for any population of individuals. Read on, study and apply the Ten Insider Tips and reap the benefits that peer-to-peer Support has to offer.

## Introduction

Hello. My name is John Pistorius. First, I want to thank you for deciding to do something positive to make a difference in your life and the lives of others. You will be blessed with new friends, acquaintances, and terrific feelings of accomplishment as you witness and experience the benefits that peer-to-peer support provides.

I'm a longtime volunteer in the disability peer support and advocacy movement in the Commonwealth of Pennsylvania, USA. I can personally attest to the amazing results that peer support can produce in a person's life. My experiences motivate me to continue in my task to assist people all over the world to start and strengthen support groups.



John Pistorius

Cognitive impairments happen every day. Although there are millions of people worldwide who experience cognitive impairments each year, only a fraction of those people ever attends support group meetings. This is partly because very few groups exist. It is also because of the negative ideas associated with 'Support' groups. Some people believe they can recover without the need for support from others.

A friend named Malin Lowenadler-Shadel put it so well when she said, "We all have peer support groups, whether it is our friends, family, or co-workers, we have people we can talk to who share common interests. The Brain Injury Alliance is like that too-people who share common interests helping each other solve problems."

**The benefits of peer support are well documented and powerful.** Sometimes the motivation to start a group is restricted by the fact that many people with cognitive impairments lack the organizational skills required to succeed. I believe the tools I've developed and this manual can improve the chances of successfully starting and running a group if used consistently.

### Improving lives

Peer-to-peer support helps people become better able to overcome barriers to their recovery by sharing compensation strategies and stories of triumph and victory. Individuals can learn to overcome recovery barriers from each other.

**"Don't walk in front of me, I may not follow. Don't walk behind me, I may not lead. Walk beside me and be my friend."**  
**-Albert Camus,**  
**French Existential Writer**

## **Further Benefits of Peer-to-Peer Support:**

**Sharing**-A peer support group is a forum where people can meet other people who have had similar experiences. Individuals benefit by networking with others who have learned the ways of the various medical, governmental and societal systems. Those who help others by sharing their successes also benefit themselves through the act and process of helping others.

**Learning**-Guest speakers can be featured to present valuable information to the attendees. Speakers can provide worthwhile knowledge, facts and data about a variety of specific subjects without cost to your group. Hand outs can be copied and distributed at future meetings too.

**Socialization**-A support group can be a place where people can socialize with others who understand what they've undergone. Social activities are another important part of a person's recovery process.

## **Getting Started**

These tips and the support group development tools will simplify the process for you. You might not want to do everything in this manual at first. That's Ok. Helping people gather to discuss their experiences can be as simple as meeting in someone's home. The point is that you get together and meet with others. Peer-to-peer support is about people sharing with one another to overcome recovery barriers.

## **My Commitment to You**

I am committed to personally assisting anyone that is interested in developing or strengthening a peer-to-peer support group. I can be reached at [jp@pabia.org](mailto:jp@pabia.org).

Feel free to contact me with any questions you may have regarding support groups. I believe this manual, the tools and my ideas can help you build or improve peer support in your area. Please send me your feedback. It is important to me.

Tell me about your success with this manual and the tools in developing or strengthening your group. Share your ideas for improvements to the tools or ideas for new tools. I'm convinced that the Ten Insider Tips and Support Group Development Tools can be used by anyone to successfully start or improve a support group. Let me know what you think.

To your success- John Pistorius

**“A man must not deny his manifest abilities, for that is to evade his obligations.”**  
**-William Feather**

## Insider Tip Number One:

### Support Begins with Respectful Language

The old children's song goes like this: Sticks and stones may break my bones but names can never hurt me. However, I submit to you that names can and do hurt people-sometimes to death.

As support group leaders and advocates for people with disabilities, we must set the standard for respectful word choices used to describe us and our loved ones. Human beings use language to communicate among themselves. Words are an efficient way to convey meaning because words condense the images and ideas we want to share with each other. It has been said that a picture is worth a thousand words. I believe the opposite is also true; words can paint a thousand pictures.

Take a moment to 'visualize' your first mental response to the following words and phrases:

- White man
- Black man
- Asian
- Black woman
- White woman
- Native American

Now examine your automatic responses to the following words:

- Sex
- Love
- Intimacy
- Money
- Prestige
- Power
- Control
- Poor
- Rich
- Respect

Do your automatic responses to those words match what you *think* you believe? Are your thoughts positive or negative? Everyone has automatic responses to words. It might take a book as thick as a telephone directory to accurately describe these automatic 'mind pictures' that occur in response to certain words.

Some phrases bring forth powerful emotions. Coupled with the ideas they represent, the words we use can encourage, motivate and inspire. Our words can also degrade, demean, devalue and humiliate others. Choosing your words respectfully when referring to yourself or others with disabilities is an important part of starting and leading a peer-to-peer support group.

**"The greatest discovery of my generation is that a human being can alter his life by altering his attitudes of mind." -William James**



## Disability Examples

Now, take a look at the following words and phrases and note your first thoughts regarding them:

- disability
- brain injury
- cognitive impairments
- speech impediments
- retarded
- memory deficits
- brain damaged
- the brain injured

The thoughts that you possess regarding these words are tied to your beliefs. Regardless of what you may tell yourself, if your belief contradicts the evidence before you, you must make a choice. No matter what you choose, your choice affects YOU, and others.

Many people are unwilling to discard beliefs that they have become comfortable with. For example, a person might work with others who are injured and experiencing severe cognitive impairments. In their work role they might not be privileged to witness the sometimes miraculous recovery that takes place outside of their work setting. The person working in this limited situation can be led to believe that 'all' persons who have cognitive impairments are the 'same.' That is, that they only reach a certain level of recovery. This belief might be comfortable in their work setting because for the most part, it could hold true. However, outside, in the real world, the belief is inaccurate. To say it is an absolute truth is disrespectful to the people.

Most people do not work within medical or rehabilitation companies. Therefore, their opinions are founded on information received through experiences in real life and media exposure. Everyone's individuality separates them from inclusion into 'absolute' categories of recovery or functionality. Yet the entertainment media promotes a limited picture of disability that disempowers the people.

When presented with new evidence about what it means to be disabled or impaired or injured, we must make a choice. Not all people who sustain Brain Injury survive. Not all people who survive Brain Injury become or remain comatose. Not all people who become responsive after Brain Injury live the rest of their life in a bed or a chair. The list of 'not all' goes on and on. Using person first language helps to get rid of the myths which restrict and oppress people.

**“Our attitudes control our lives. Attitudes are a secret power working twenty-four hours a day, for good or bad. It is of paramount importance that we know how to harness and control this great force.”**

**-Tom Blandi**

## Person First Language

Do you like being called a black man or a white woman or a disabled person? Or do you prefer to be called a person by your name? If I call out to you on the street, do you want others to say, "Hey disabled person!" or "Hey cripple!" or anything else in reference to your disability?

Do you have your loved ones refer to you by your hair color or any other physical characteristics? Or do you prefer to be called by your name? The same concept holds true for others. They expect courtesy and respect. Calling persons anything other than people or anything other than by their name is disrespectful.

The most popular argument against using respectful language choices is that 'political correctness' is transitory. Political correctness is a fluctuating concept; however, being respectful is a stable concept. It remains stable through all 'politically correct' storms. If my name is James and you call me Jimmy and I ask you to call me Jim and you continue to call me Jimmy, you disrespect me. If my skin is dark, I expect that you will not use any of the derogatory terms which were historically used to refer to people with dark skin. This is also true with people who experience disabilities.

The labels that are used to identify medical conditions and treatments are ordinarily not relevant in society. They are usually unimportant to anyone but medical practitioners and other service providers in society. However, sadly, individuals often get caught up in the practice of using medical labels to describe themselves or their loved ones to others. This practice is hurtful because it promotes negative attitudes about the person being labeled. Elevating the disability label before the status of the individual reduces the significance of the person being referred to.

People who wear contact lenses do not tell everyone they meet that they are 'poor-sighted' or that they are using lenses to correct their vision. Neither a parent nor spouse would tell others these things. People with boils on their backside do not tell everyone they meet of their condition. Neither do their loved ones tell others. People that experience brain injury and their loved ones must stop the practice of telling everyone they meet in society about their brain injury. It really is not relevant.

We must also stop the practice of calling people with disabilities "the disabled," "the crippled" or "the brain damaged," "afflicted" or anything other than people first. If it is relevant to describe oneself or loved one in reference to their disability, the respectful way is to use the person's name first. In reference to a group of individuals with disabilities, using the word 'people' or 'person' before the disability is the most respectful way to speak or write.



**“Minds are like parachutes -  
they only function when open.”  
-Lord Thomas Dewar**

## **Examples:**

- A person with a disability instead of a disabled person.
- The people with disabilities instead of disabled people.
- A person in a coma instead of comatose patient.
- A person who is non responsive or minimally responsive instead of vegetative or vegetable.
- The people who experience brain injury instead of the brain injured.
- Individual who experienced TBI or individual recovering from TBI

Using person-first language is always respectful when used with affirming terminology. It has nothing to do with being politically correct. It's about respect. Regrettably many people refuse to accept this.

## **Recovery Happens**

To be sure, Brain Injury complicates life for the people who experience it. Some people do not fully recover from the injury. However, many people who sustain and survive TBI overcome recovery barriers well enough to lead satisfying, productive lives in society. Regardless of evidence to the contrary, many people continue to hold onto their incorrect beliefs in the forecasters who predict that certain outcomes are absolutely inevitable. They perpetrate their inner beliefs on others through the use of demeaning word choices, negative phrases and the order of their words.

## **Language Patterns**

Our language affects our beliefs. It is one way that we can change the prevailing beliefs in society at large. To change 'absolute' thought patterns, one only needs to change the way that they refer to people. By refusing to hold on to 'absolute' thinking patterns, the prejudicial belief that 'all' people who sustain Brain Injury are "the same" and therefore will always be similar can be undone.

Looking again at the history of race relations in this country, we see a marked change in language as one of the most powerful examples of shifting beliefs. We can all remember words that were once accepted in reference to people whose skin is darker than others. Those words are no longer used in media and society at large because of the demeaning nature of the 'thoughts' they produce when used. The same thing holds true within the population of people with disabilities.

## **Time for Action**

It is time to stand up for what is right and to decry the use of demeaning language in reference to people with disabilities. By insisting upon the removal and disassembly of language barriers, support group leaders can make changes within society, the media, government and each other. The truth is; People with disabilities are not worth less than others who have yet to experience disability. Disability is a normal, natural part of life. By insisting upon and using affirming language, support group leaders set the standard.

## Human or Vegetable

A 'non responsive' prognosis does not eliminate a person from belonging to the human race. A coma does not shift us from human to vegetable status. Brain Injury is not the end of life. It is the beginning of life *after* brain injury. This simple change in reference can make a profound difference in someone's life.

Eliminating language barriers will free more people with disabilities to enjoy the freedoms and rights guaranteed to them by the Constitution of this great nation. And isn't that what is right for everyone?

As a support group leader you play an important role in affirming people and providing a forum that assists them in their recovery. Using positive references to people and insisting upon the use of person first language is an influential and important part of your position. Some people will model your example while others will need to be nudged into being respectful. Knowing is the first step. Acting upon your knowledge is the beginning of wisdom.

Human lives hang in the balance. Choose Affirming Language. Stand for respect and dignified treatment of all persons with or without impairments that limit ability. Dismantle language barriers and free people from the restrictions that language places on them.

Peer-to-peer support is about people sharing their knowledge and experiences with each other to overcome recovery barriers and obstacles to independent living. Share your knowledge of how what we say and how we say it affects others.

In time, your example will serve to help others to better understand why it matters. By sharing your knowledge of affirming language choices, you will shed the light that overcomes the darkness of oppressive language references.



**“It is no exaggeration to say that every human being is hypnotized to some extent, either by ideas he has uncritically accepted from others, or ideas he has repeated to himself or convinced himself are true.”**

**-Dr. Maxwell Maltz**

## **Insider Tip Number Two:** Recognize the Need for Peer Support

Millions of people live with cognitive impairments brought about by a multitude of means. The Centers for Disease Control (CDC) recently reported that each year in the USA, at least 1.4 million people sustain a TBI. Of these, about 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an emergency department (ED).



- Approximately 475,000 TBI's occur among children ages zero to 14 years.
- Falls are the leading cause of TBI; rates are highest for children ages zero to four years and for adults age 75 years or older.
- Each year, TBI causes an estimated 80,000 to 90,000 people to experience permanent disabilities.
- Adults age 75 and older have the highest rate of TBI-related hospitalization and death.

(Source: [http://www.cdc.gov/ncipc/pub-res/TBI\\_in\\_US\\_04/TBI-USA\\_Book-Oct1.pdf](http://www.cdc.gov/ncipc/pub-res/TBI_in_US_04/TBI-USA_Book-Oct1.pdf).)



The people who survive could benefit from attending peer-to-peer support groups. Unfortunately, many of them live with the consequences of their impairments alone because they can't find a support group near enough to attend. Transportation issues act as barriers also because many people can't attend meetings unless someone else drives them and because public transportation is unavailable.

Many people living with cognitive impairments express loneliness, sadness and frustration. Their feelings of isolation can increase during stressful times. Everyone has a need to belong where they can share their successes and even failures without criticism. Sharing experiences helps people to cope. This makes your group important to those who experience brain injury.

A support group setting can be a place for people to express themselves if they have access to the meetings and the information presented or provided. It can be a forum for learning how to work through the difficulties of cognitive impairments. Spending time with people who understand and accept impairments can be liberating. It can be the first step to recognizing recovery barriers in society. Some people become involved to redefine their purpose and to increase feelings of self-worth. Others recovering can become better equipped to overcome barriers to living productive, satisfying lives.

**"It matters if you just don't give up."- Stephen Hawking**

## Every Group Counts

With so many people needing support, people are joining forces with one another and their family members and friends to start new groups. Starting a group in your area will improve the chances of people having meetings that they can attend. By following these Ten Insider Tips and using the Support Group Development tools, you can easily start a successful group.

Once you get started, you might be able to help others find rides to meetings. Members can provide rides to other members. You can ask other people you know for help to get the group going. Anything you do to help can make a difference for someone else.

You can ask doctors and other professionals to speak about certain topics. By giving them a forum to speak, you help them improve their image in the community. You also help your members learn more about various subjects without charge. It is a winning arrangement for everyone.



You can give merchants and other companies a chance to improve their public image too. Just ask them to donate some refreshments or to buy some postage stamps for your group. You can also ask local merchants to provide gifts to be used as door prizes for holiday celebrations.

Donations don't need to be in the form of money. Anything that helps your group succeed can be donated by individuals and companies to assist you. All you have to do is ask them. We have had companies supply food for parties. We have had corporations donate airline tickets and hotel rooms for our leaders to attend conferences. We've had people donate printing services and printing costs for newsletters.

By studying the Ten Insider Tips and using the Support Group Development Tools, you can quickly begin and lead a successful peer-to-peer support group. It doesn't need to be a massive collection of people in one place. You can have as few as three or four people to get started.

**“Determine what specific goal you want to achieve. Then dedicate yourself to its attainment with unswerving singleness of purpose, the trenchant zeal of a crusader.” -Paul J. Meyer, Author, Motivator**

### **Insider Tip Number Three:**

#### Plan Your Work

Whether you start a peer-to-peer support group or you work to strengthen a group that already exists, you will need to get organized. This is probably the most important part of the process when getting started. Remember that you will be making a positive difference to other people with cognitive impairments and their families. Thank you for spending your time to do this.

Being and remaining organized is an important part of starting and leading a peer support group. A binder or notebook with labeling tabs is a useful tool. You can use your binder to organize your thoughts and your work in one place.

#### **Questions to consider:**

- Can I help to improve an existing group or do I need to start one?
- If you are unsure of the existence of a peer support group in your area, you can do one or more of the following things to find out:
  - Contact the Brain Injury Association in the USA by calling 1-800-444-6443.
  - Contact the International Brain Injury Association by calling + 703.683.8400.
  - Contact the United Way, Red Cross and other human service organizations.
  - Search your local telephone directory.
  - Search online by using a search engine with the name of your town, state and country and the words Brain Injury Support Group in the search box.

If you learn of a group in your area, offer your assistance to the contact person. Share the support group development materials you have received from us. Most support group coordinators will be happy to have you volunteer your time and energy to help improve the group.

If you do not learn of a group, or it is too far away, and you want to start a new group, locate an accessible meeting place. Make sure that a person using a wheelchair or other mobility device like a walker or a cane, and those who have difficulty walking will be able to get into the building smoothly. Check to insure that the restrooms are able to be used by people with mobility aids also. Physical accessibility is an absolute necessity for successful peer support groups.



PLAN  
YOUR  
WORK

**"To be prepared is half the victory."  
-Miguel de Cervantes**

**Refer to the following list when you begin seeking a meeting place:**

- A. Local libraries,
- B. Social or a fraternal club hall,
- C. A social hall in Churches or other religious structures,
- D. Other public buildings/meeting rooms, restaurants,
- E. Someone's home, or
- F. Hospital or rehabilitation company meeting rooms.



**More Questions to Ask.**

1. Am I willing to commit my time and energy to do what it takes to successfully create and lead a peer support group? If so, how much time?
2. Am I willing to invest my money to get things going? If so, how much? (It doesn't take much to get started.)
3. Will this group focus on peer-to-peer discussion, guest speakers or both? Most groups schedule speakers occasionally to cover topics of interest and concern. However, some groups exist solely for the discussion between peers and social activities. Either way, people benefit from getting together regularly.
4. Will we meet once each month or twice?
5. Will we plan social gatherings, dances, parties and outings?
6. What is my purpose for developing a new group or strengthening an existing group?
  - a. To learn about cognitive impairment?
  - b. Educational opportunities?
  - c. Medical service referrals?
  - d. Social support?
  - e. Strategy sharing?
  - f. Advocacy?
  - g. Camaraderie?
  - h. Meeting others for friendship?
  - i. To learn how to overcome barriers to living a fuller more productive life?
  - j. Because it needs to be done and I'm the one who can do it?

Your purpose might include any one of the above concepts or all of them. Your group can start with one or more ideas as its purpose and gradually expand to include more ideas as it grows. The point here is to get started! People will benefit from the group you start and so will you!

**“Planning is bringing the future into the present so that you can do something about it now” - Alan Lakein**

## Whom can I ask for help?

As with any new endeavor, sharing the tasks can simplify the process. Ask yourself: Do I know anyone who might be willing to work with me? Here are some ideas:

- a. Family members
- b. Friends
- c. Other people experiencing cognitive impairment
- d. School nurses
- e. Medical company employees
- f. Librarians
- g. Social workers

## Will your group serve refreshments?

If so, what kind? Here are some ideas:

- A. Fruit juice, water, coffee, tea, soda
- B. Fruit or vegetables (in season)
- C. Pastries
- D. Fresh baked foods
- E. Cookies, candies, chips
- F. Other local food favorites



You can ask local merchants, markets, delicatessens, and restaurants for refreshment donations. Use the Donation Letter tool. Promise merchants publicity and word of mouth advertising as a way to thank them.

You can put the name of the business that donates refreshments on your meeting notices and the meeting reminder post cards that you send to members. (Example: Refreshments Provided by Joe's Market) Remember to send your contributors a copy of anything that includes the 'thank you' message to encourage them to donate again!



Some of the questions in this section are easy to answer. Others may take some time. The answer can depend on the meeting place and the amount of time you are willing to invest. Once you get started, the satisfaction you receive will make it seem easy!



**“Obstacles are those frightful things you see when you take your eyes off your goal.”**

**- Henry Ford**

## Insider Tip Number Four:

### Organize Your Tools and Work Your Plan of Action

Study this Insider Tips Guide. Take notes in your notebook/binder. The tools are organized in folders on the CD. Each folder is named for the software used to create the tools in that folder. All of the tools have been converted to the Portable Document (PDF) file format. You can look at every tool, regardless of the original software used to create it. You can print them out as-is or you can open the Word or WordPerfect documents and use your word processor to modify them to suit your taste. All that I ask is that my contact information remains on each document.



1. View the PowerPoint Presentation entitled Starting and Facilitating a peer-to-peer Support Group. You will need to use PowerPoint or the free PowerPoint viewer software you can download from <http://www.microsoft.com/downloads/>.
2. Review the document list in the Adobe Acrobat Folder. This folder contains all of the tools created to date. They are in PDF (Portable Document Format.) You will need to use the free Adobe Acrobat Reader Software which you can download from <http://www.adobe.com/>.
3. After viewing the PowerPoint presentation and reviewing the Adobe Documents, You can print whichever tools do not need to be personalized by opening them and clicking the print button. The following tools can be used in their generic state:
  - a. Welcome Poster
  - b. Phone Call Log
  - c. Restroom Directional signs (left or right arrows)
  - d. Sign-in Sheet
  - e. Speaker Evaluation
  - f. Three Arrows Directional Posters (left or right)
  - g. Single Arrow Directional Signs (left or right)
4. The following tools will need to be customized with your specific group name, meeting date, time and contact information.
  - a. Meeting Notice Poster Template
  - b. Meeting Notice Post Card Template
  - c. Business Card Template
  - d. Facts About Head Injury Brochure



## Customizing the Tools

Once you become comfortable in your role as meeting leader, you can customize any or all of the tools to include your group name. These tools can be altered to suit your taste, so long as my contact information remains intact. This is how I reach others to freely distribute the tools and start new groups.

If you have the Microsoft Word Program, you can open the Word documents, review them and add your group name and contact information to personalize those tools.

If you have the WordPerfect program, you can open the WordPerfect files and customize them to include your group name and contact information. You can be

organized quickly and easily and save your time and energy by using the Support Group Tools I've created. If you need any help customizing your tools, please feel free to contact me at [jp@pabia.org](mailto:jp@pabia.org).

Please remember to make your request for help as specific as possible and include your name and contact information. Also, feel free to ask me questions regarding my experiences in operating and starting peer support groups.

Please do not send attachments. I will not open them. Due to the large volume of mail I receive, and the ever-increasing threat of virus infections, all letters with attachments are automatically discarded.



**“Our deepest fear is not that we are inadequate. Our deepest fear is that we are powerful beyond measure. It is our light, not our darkness that most frightens us. Who are we not to be brilliant, gorgeous, talented and fabulous? You are a child of God. Your playing small doesn't serve the world. We were born to make manifest the glory of God that is within us. It's not just in some of us; it's in us all.” -Nelson Mandela**

## Working Your Plan

Once you decide to start a new group or strengthen a group that has already started, you can work the following plan of action to proceed. You can also incorporate your own insights and ideas into the plan to improve your group.

1. After you have found a suitable meeting place, choose a day and time to meet. Consistency is important in this area. It is easier to secure a meeting room for a day of every month like the first Tuesday (or any other day for that matter.) It is also easier for a person to keep track of your meeting if it is planned for the same day of the month. Ask people to mark your meeting day on every month in their calendar to improve attendance.
2. Contact local business owners to ask for their help. Be specific. Consider the following possibilities:
  - a. Food and beverage donations
  - b. Paper plates, cups and napkins
  - c. Postage donations
  - d. Printing or copy service donations
  - e. Paper for meeting notices
  - f. Space to post meeting notices
  - g. Donations for anything you need to run the group

**Get the Word Out** -After you locate a meeting place and set the day and time, notify your local news media. Most newspapers will publish your notice if you get it to them in time. Call your local media sources. Be polite, yet persistent.

**“The difference between 'involvement' and 'commitment' is like an eggs-and-ham breakfast: the chicken was 'involved' - the pig was 'committed'.”**

**-Author unknown**

Find out who the contact person is that handles public meeting notices or health related meeting notices. Make sure you get a postal address and their email address if possible. If you get your notice to the proper contact person, usually a staff writer or Editor, you can expect to have it published. Meeting notices help people find your group and get more people to attend your meetings. (See Insider Tip Number Five for more information about this topic.)

## Peer Support Defined

- Regular Group Meetings
- Peer-to-Peer Interaction
- Conveying Information
- Service Referrals
- Strategy Sharing/Expanding
- Camaraderie
- Advocacy
- Social Activities



## Insider Tip Number Five:

Announce, Publicize, Promote, Broadcast and Publish your Meeting Notice

One of the most important things you can do is let people know about your group. You need to broadcast meeting notices to inform people and get them interested in attending. Here are some ideas for advertising your meeting.

1. Modify the Meeting Notice Poster template to include your group name, the meeting place, the day and time that your group meets, who to contact for more information and the phone number for the contact person. Make sure that the meeting Notice Posters include the day of the month and time. Be sure to include tear-off sections to make it easier for people to keep your contact information.
2. Receive permission to hang your poster at your local public library, general hospital, rehabilitation facility, place of worship, grocery store, convenience store, local newspaper office, and other public places including schools. Many merchants will permit you to post a notice in their store window. Many places have bulletin boards for community notices. Apartment buildings might have space available for posting notices near mailboxes or in other common areas like dining rooms and lobby areas.
3. Once your support group has started, you can gather postal addresses and email addresses with the Telephone Log tool and Meeting Sign-in Sheet tool. Use these tools to improve attendance by sending out notices to people who call you or visit your group. Use email to save postage whenever you have an email address to inform people of future meetings and events.
4. Some group leaders call members to remind them of meetings. This is easy to do when your list is small. Use the Telephone Log tool to keep track of people you have called. Use a separate log sheet to keep a record of people who have called you. Ask others to call some of your members each month to make it easier to get the work done.



**“Always look at what you have left.  
Never look at what you have lost.”  
-Robert H. Schuller**

## More Publicizing Ideas

5. Ask your local Brain Injury organization if they have a directory of support groups. If so, ask them to list your group and contact information, including a telephone number and email address if you have one.
6. Contact your local television stations and cable or satellite companies and ask if they have free community service bulletin boards. If so, ask them how to have your meeting notice broadcast to subscribers. You will be surprised how quickly you can do this.
7. Read the Article entitled **How to Write a Press Release** by Luan Aten. Read the article entitled, **Writing Press Releases**, by John Pistorius. Then modify the Press Release Template tool to include specific information about your group. Be sure to include the following:
  - a. Name and telephone number of the contact person.
  - b. Group name.
  - c. Meeting place address.
  - d. Date and time of meeting.
  - e. Topic of discussion or
  - f. Guest speaker name and topic of speaker's presentation.
  - g. Brief description of your group, or statistics regarding the incidence of brain injury in your region.
8. Send your Press release to your local news media contact persons.
9. If your area has a local shopping magazine, Penny Saver, Penny Pincher or other such ad magazine, get your group listed.
10. Some areas have a Help section in the telephone directory. Contact the telephone company to get your group listed.
11. Be creative. Look for ways to inform people about your group. The more people you reach, the more people your group can attract.



**“One of the most difficult things to give away is kindness, for it is usually returned.”**  
- Mark Ortman

## **Insider Tip Number Six:**

### Contact Local Government Representatives

This is another area where you can gain support for your group. By letting the politicians know about your group, you can give them an opportunity to help you reach people who will benefit from attending meetings.

To learn who your government officials are:

- Look in your local telephone directory.
- Visit your Town Hall
- Search the Yahoo and Google Search Engines



Once you find contact information for your representatives, notify them in writing of your new peer-to-peer support group. Follow up with a visit to their local office. Receive permission to leave brochures and business cards (which you have added your contact information to).

By networking with local government representatives, you are giving them a chance to improve the community they serve and boost their public image. Improving their public image is an important motivation. They want to get reelected.

Their motivation can help you get them to grant you money or services to help your group also. All you need to do is ask. You will never know what kind of help you can receive unless you ask.

**“To laugh often and much; to win the respect of intelligent people and the affection of children; to earn the appreciation of honest critics and endure the betrayal of false friends; to appreciate beauty, to find the best in others; to leave the world a little better; whether by a healthy child, a garden patch or a redeemed social condition; to know even one life has breathed easier because you have lived. This is the meaning of success.”**

**-Ralph Waldo Emerson**

## **Insider Tip Number Seven:**

### Network with Local Hospitals and Medical Centers

People are sustaining injuries and experiencing cognitive impairment all over the world every day. Local hospitals treat people who can benefit from attending peer-to-peer support group meetings. You can reach these people by locating medical service providers in your area.

Hospitals, rehabilitation centers, doctors and social workers are all able to help you reach the people that will be served by your group. Reach medical service consumers via trauma centers/medical facilities and Veterans Hospitals also.



To reach people who are treated by medical professionals you will first need to locate the professionals in your area. The following sources can be useful in helping you get to the people who can help you reach people who can benefit from peer support in your area.

- Telephone Directory
- Word of Mouth (Where do other people in your area seek treatment?)
- Social Work Schools/Training Centers
- Medical Schools

Once you locate the medical service providers in your area, ask them to help you reach the people who experience cognitive impairments. Social workers are usually very resourceful in helping. Give them your contact information. Ask them to offer your brochure and business card to people who are treated for head injuries, concussion, falls, motor vehicle injuries, sports injuries, domestic violence, and other potential causes of injury and cognitive impairment.

Remember the causes of cognitive impairments can differ. Also, the degree of impairment can vary greatly. Oftentimes, mild to moderate injuries may be overlooked by the professionals.

You can reach the persons who can benefit from your group by networking with the employees of the various companies that treat the causes of brain injury.

**“Real difficulties can be overcome; it is only the imaginary ones that are unconquerable.”**

**-Theodore N. Vail**

## Concussion -The Hidden Brain Injury

Because of the hidden nature of cognitive impairments, it is important to reach people who sustain concussions. There are many causes of concussion, head injuries and resulting brain injuries.

- Motor vehicle accidents
- Falls
- Things Falling on the Head
- Sports related bumps on the head and temporary knock out.
- Domestic violence (Both male and female victims)
- Child abuse
- Street violence
- Saloon/Tavern violence



In short, anytime the head hits something or something hits the head, the person might sustain a mild to moderate injury to their brain. Even sudden jarring can injure the brain. This is the cause of shaken baby syndrome and many sports related injuries.

The functional limitations people experience can reduce their quality of life. The individuals you reach will be glad to find your peer support group. The main purpose of the group is to provide a forum where people can meet to share and receive information. The outcome can be that attendees learn to live more productive lives by maximizing their abilities to live in the least restrictive environment possible. This can only happen if they are able to find your group.

Throughout the many years of my involvement, I have had the privilege to meet countless numbers of people who have experienced Brain Injury who came from all walks of life.

### **Brain Injury is *always* nondiscriminatory.**

Regardless of national origin, young or not, male or female, rich or poor, everyone alive is a candidate.

This fact makes it very important to develop peer support groups. The need for groups far exceeds the supply.



## Insider Tip Number Eight:

Contact and Network with Schools, School Nurses, and Athletic Directors.

1. Many school children bump their heads during the course of their education. School nurses are usually the first medical service providers that come into contact with these children. School nurses can distribute your brochure and business card to parents whose children bump their heads.
2. You can speak with athletic directors. Tell them about sports injuries and concussion. Give them a copy of the article, **Football Players and Concussions: Too Much Too Soon?** By J. L. Reed. It is on the Tools CD in the 'Articles' folder which is in the 'Adobe' folder. "Football players who sustain concussions have almost three times the risk of sustaining a second concussion during the same season compared with uninjured players . . ."
3. You can give a presentation to students. Effective topics include:
  - a. Prevention through helmet use;
  - b. Prevention through seat belt use;
  - c. Don't let it happen to you;
  - d. Symptoms of brain injury;
  - e. Awareness campaigns
  - f. Peer support demonstrations.

Be creative! The presentation you give might be the only link your audience has to accurate information pertaining to brain injury.

**The work that you do  
can help people live fuller,  
more productive lives!**

## Why Does it Matter?

■ People recovering become better equipped to overcome barriers to living productive, satisfying lives.



## **Insider Tip Number Nine:**

### **Establish a Regular Course of Action**

Once you set the day and time of your meeting, make sure you always start your meetings on time. Remember to stick to a regular schedule, such as the first Tuesday or second Thursday of every month. Any day of the week can work. You can meet on any day of the month that works for you and others. By maintaining the same day and time each month, people can easily plan to attend each month. This is especially important to those who depend on others for transportation and those who use public transportation systems.



### **To set up each meeting:**

- Give yourself at least 20 minutes to prepare the meeting place.
- Put Welcome posters at each door where attendees need to pass through.
- Put directional signs where needed to help members to find the meeting room and rest rooms.
- Arrange informational articles and brochures on a table for members to see and pick up.
- If you provide refreshments, have them arranged where people can get to them without disturbing the meeting or speaker. Keep your donation container where members can see it when helping themselves to refreshments.
- Have your sign-in sheet available with a pen or pencil. Ask everyone to sign in when they arrive or pass the sheet around after everyone settles in.
- Pass out Meeting Evaluation or Speaker Evaluation forms.
- Once everyone gets settled in, begin the meeting by introducing yourself. At the first few meetings you can give a brief explanation of why you started the group.
- Share meeting guidelines or values with attendees.
- Offer attendees a chance to introduce themselves.
- If you have a speaker/presenter, introduce them and their topic. Then turn the meeting over to the speaker.
- If you are having a discussion meeting, open the meeting with a topic. Some common general topics include:



- |                          |   |
|--------------------------|---|
| • Employment             | • Compensation Strategies               |
| • Physical Accessibility | • Cognitive Accessibility               |
| • Education              | • Social Activities                     |
| • Therapies              | • Any topic the group wants to discuss. |

## Wrapping up the Meeting

Once the speaker finishes, or when the agreed upon time-limit is reached, politely thank the speaker and begin clapping. Others will join in. Politely ask attendees to complete the Meeting/Speaker Evaluation form and leave them at the refreshment's table.

After the meeting, socialize with your members. Encourage them to come again next month. Ask them if they have marked the meeting day and time on their calendar. Give them the dates of upcoming meetings and remind them to mark their calendar.

When finished, ask for help in cleaning up. Also, take notice of the people who automatically help. They are the ones you can count on in the future for more help in strengthening the group. These are also the people who might be willing to start a group in their town. Encourage participation to help develop leadership.

Some will quickly volunteer. Remind attendees that helping with the group will give them a chance to meet people. Volunteering will give them activity that helps them to socialize with others. Getting help can make running the group easier for you too.

Be encouraged when anyone even considers helping you. Sometimes it takes time for a person to get to know you and to feel comfortable lending a hand.



**“A 5-watt lightbulb is barely visible, a 5-watt laser burns through steel. Learn to concentrate your energy and watch the magic that follows.”**  
-Ed Strachar



## **Insider Tip Number Ten:**

### **It Starts With You Making Accessibility Real**

A peer-to-peer group is an important place for people who experience cognitive impairments and their families. Making your meetings accessible means eliminating all barriers to participation. It means reaching people and accommodating them.

If you apply the information contained within these Ten Insider Tips, you will reach many people who can benefit from peer support. Getting your group to become well known will improve your chances of reaching people. Of those that you reach, some will not be ready to attend meetings. Others might never come. Some who attend may not be ready to participate in discussions. Still, be encouraged by those who attend, those who join in conversations and people who become involved and make your meetings accessible.

Unless you do what needs to be done to make your meetings accessible, people will not feel as if they belong. Each Tip offers multiple ways to improve your successful peer support group development. Each is important, but none of these tips will matter if your meetings are not accessible.

Your dedication will be met with success if you remain focused and determined to bring people together in an accessible manner. Becoming accessible means removing barriers that prevent accessibility.

1. Study the Ten Insider Tips and take notes.
2. Watch the PowerPoint Presentation and take notes.
3. Study the 32-page brochure, "Making Accessibility Real: Guidelines for Meetings, Conferences and Gatherings" that identify a generic approach to the development of improved accessibility strategies for meetings. It can be found at <http://www.hcbs.org/> by typing 'accessibility' in the search box. This tool is indispensable for learning how to make meetings accessible.
4. Refer to the Ten Insider Tips and the Accessibility Guide to refresh your understanding and to establish your routine. Pay close attention to the accessibility needs of your attendees.
5. Use the Support Group Development Tools to better your organization and to improve the accessibility of your meetings.
6. Tell everyone you can about your group. Anyone you know or that you meet might know someone who experiences cognitive impairment. Unless you tell people, they might not learn about the group. They can't attend if they don't know that the group exists.
7. Get your attendees to tell others too. Word of mouth advertising is a great way to improve access to your meetings.
8. When in doubt about needs for accommodation-ask!

**“From what we get, we can make a living; What we give, however, makes a life.” - Arthur Ashe**

## Wrap-up

Some people ask; “What makes a Peer Support Group successful?” Everyone defines success differently. Eliminating barriers and holding cognitively accessible meetings will go a long way to improving your chances of having a successful group. The very act of starting and leading the meeting can help the founders to build skills that will improve their life.

If you are able to share information that one person can use to enrich their life, you are successful. Even when the improvement seems minor to you, it is important to them. In turn they can have a dynamic, positive impact on others. That is the multiplying power of peer support.

Reaching people and increasing attendance can be considered successful. Some people will not have received any type of support at all before attending your group. People who feel like they ‘belong’ can lose the hopelessness that might plague them. If attendees are not accommodated in an accessible fashion, they will likely stop attending.



You can measure your success by keeping track of the number of people who call you. You can measure the success of your group by keeping a record of attendees. You can measure the success of your group by writing down comments that people make about your group. And you can measure the success of your group by the way you feel when you see unhappy faces turn to smiles.

Cognitive impairment and the causes are getting more attention in movies and television programs. Each media presentation raises awareness a notch. By starting or strengthening a peer support group, you are doing your part to help others and yourself. You are making a positive difference in your corner of the world. And that really matters.

Whether you have four or forty members, people will learn from one another and lives will be forever changed. And remember that it all started with you!

For all of the people that you and your group will serve, I thank you.

John Pistorius

**“Read every day something no one else is reading. Think every day something no one else is thinking. It is bad for the mind to be always a part of unanimity.”**

**-Christopher Morley**

## RESOURCES

International Brain Injury Association + 703.683.8400.

BIA USA Family Helpline: 1-800-444-6443

National Aphasia Association 1-800-922-4622

Brain Tumor Information Line 1-800-934-2873

### Website Resources

[www.internationalbrain.org](http://www.internationalbrain.org)-International Brain Injury Association

[www.bisga.org](http://www.bisga.org) -Brain Injury Support Group Alliance

[www.biausa.org](http://www.biausa.org) -Brain Injury Association of America (BIA)

[www.aphasia.org](http://www.aphasia.org) -Aphasia Association

[www.braintumor.org](http://www.braintumor.org) --Brain Tumor Org.

[www.braintrust.org](http://www.braintrust.org) -The Healing Exchange Brain Trust

[www.headinjury.com](http://www.headinjury.com) --Brain Injury Resource Center

[www.adapt.org](http://www.adapt.org) --Community Services Activists

[www.afb.org](http://www.afb.org)-- American Foundation for the Blind

[www.adawatch.org](http://www.adawatch.org) --Defends the Americans with Disabilities Act (ADA)

[www.dredf.org](http://www.dredf.org) --Civil rights organization

[www.wapd.org/links/index.html](http://www.wapd.org/links/index.html) -hundreds of links to more resources

[www.caregiver.org/](http://www.caregiver.org/) -Family Caregiver Alliance

<http://c-c-d.org/> -Public Policy Advocates

<http://www.fctd.info/> -Family Center on Technology and Disability

**An ant on the move does  
more than a dozing ox.  
-Mexican proverb**

**“In the end, we will remember not the words of our enemies, but the silence of our friends.”**

**- Martin Luther King Jr.**

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## TEN INSIDER TIPS



A Manual  
For Starting or Improving  
a peer-to-peer  
SUPPORT GROUP

Freely offered by

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