



# **STOP THE CLOT® SUPPORT GROUP**

*Leader's  
Guide*

## Contents

ACKNOWLEDGEMENTS.....	3
DEFINITION OF KEY TERMS.....	4
INTRODUCTION.....	6
National Blood Clot Alliance (NBCA) Mission.....	6
Purpose of this Guide.....	6
Need for Support Groups .....	6
STC Support Group Goals .....	7
SUPPORT GROUP OVERVIEW .....	9
Purpose and Description of a Support Group .....	9
Leader Guidelines .....	10
STARTING A SUPPORT GROUP.....	11
Starting a Support Group: Benefits and Skills .....	11
Leader Responsibilities .....	11
What You Need for Success as a Leader.....	12
Getting Ready .....	14
SUPPORT GROUP MEETING .....	15
First Support Group Meeting: What to Expect .....	15
Setting Ground Rules .....	15
Meeting Structure and Format .....	16
Delegating .....	17
Items to Plan Ahead .....	17
Guest Speakers.....	18
Potential Meeting Topics .....	19
How to Promote and Publicize .....	19
Membership Ups and Downs.....	21

LEADING GROUP DISCUSSION .....22

    Guidelines for Leader Effectiveness .....22

    How Best to Ask Questions .....23

    Challenges of Leading a Group.....24

    How to Keep a Meeting on Track .....26

CONCLUSION .....33

APPENDICES: RECORDKEEPING.....34

## ACKNOWLEDGEMENTS

National Blood Clot Alliance (NBCA) wishes to thank the following volunteers for their commitment, time and work in developing this guide.

Pat Koppa, MPH, Chair, STC Support Group Task Force  
President, Public Health Consultants, LLC  
Minneapolis, Minnesota

Karen Boyd, MSW, LMSW, DCSW  
Michigan State University  
Center for Bleeding and Clotting Disorders  
East Lansing, Michigan

Laura Earl, RN, BSN, CACP  
University of New Mexico Hospitals  
Anticoagulation Services  
Albuquerque, New Mexico

Ruth Ann Kirschman, RNC, WHNP  
Comprehensive Family Medical Center  
Denver, Colorado

Ruth Morrison RN, BSN, CVN  
Brigham and Women's Hospital  
Venous Thromboembolism Research Group  
Roxbury Crossing, Massachusetts

Joni Osip, RN, MS  
University of Minnesota  
Center for Bleeding and Clotting Disorders  
Minneapolis, Minnesota

Mary Ellen McCann, RN, MA  
NBCA Director of Health Learning and Marketing  
Tarrytown, New York

This manual was supported by Cooperative Agreement U27 DD00326 from the Centers for Disease Control and Prevention.

## DEFINITION OF KEY TERMS

These are terms that relate to blood clots or disorders that increase the likelihood of forming a clot. It is important to know how to respond to the signs and symptoms of clotting or pulmonary embolism.

- **Thrombosis** is when a blood clot forms inside a blood vessel.
- **Thrombophilia** is a blood clotting disorder that may cause blood clots to form more easily than in a person without a clotting disorder.
- **Deep vein thrombosis (DVT)** means a blood clot forms in the deep veins, usually in the legs.
- **Pulmonary embolism (PE)** is serious and happens when a blood clot breaks off and travels to the lungs. It is a medical emergency, because it can block blood flow to the lungs. PE causes death in about 1 out of every 3 people.
- **Venous thromboembolisms (VTE)** is an umbrella term for DVT and PE.

<b>SIGNS AND SYMPTOMS</b>	
Deep Vein Thrombosis (DVT)	Pulmonary Embolism (PE)
The clot usually forms in the leg	The clot travels from leg to lung
Between 350,000 and 600,000 Americans each year develop DVT/PE, and at least 100,000 deaths per year are thought to be related to these diseases	
<ul style="list-style-type: none"> <li>• Swelling, usually in one leg</li> <li>• Pain and/or tenderness at the site</li> <li>• Reddish or bluish skin discoloration</li> <li>• Warm to touch at site</li> </ul>	<ul style="list-style-type: none"> <li>• Sudden shortness of breath</li> <li>• Chest pain-sharp, stabbing; may get worse with deep breath</li> <li>• Rapid heart rate</li> <li>• Unexplained cough, sometimes with bloody mucus</li> </ul> <p>Get medical help <i>right away</i> for these symptoms</p>

[www.stoptheclot.org/stopligh.htm](http://www.stoptheclot.org/stopligh.htm)



National Blood Clot Alliance

(877) 4 NO CLOT  
[www.stoptheclot.org](http://www.stoptheclot.org)

**Stop The Clot®**

## CLOTTING RISK: What You Need to Know



**Blood Clots**

**Stop!**

Discuss with your doctor now.

### HIGH RISK

- Hospital stay
- Major surgery, such as abdominal/ pelvic surgery
- Knee or hip replacement
- Major trauma: auto accident or fall
- Nursing home living
- Leg paralysis



**Blood Slows**

**Caution!**

Talk with your doctor about risk.

### MODERATE RISK

- Older than age 65
- Trips over 4 hours by plane, car, train or bus
- Active cancer/chemotherapy
- Bone fracture or cast
- Birth control pills, patch, or ring
- Hormone replacement therapy
- Pregnancy or recently gave birth
- Prior blood clot or family history of a clot
- Heart failure
- Bed rest over 3 days
- Obesity
- Genetic/hereditary or acquired blood clotting disorder



**Blood Flows**

**Go!**

Stay alert to any change in risk.

### AVERAGE RISK

- Active
- Younger than age 40
- No history of blood clots in immediate family
- No conditions or illnesses that heighten clotting risk

## INTRODUCTION

*Melissa J., a 38-year-old librarian and mother of two, was recently diagnosed with a blood clot in a vein in her right leg. Although her health care providers spoke with her about blood thinners, INR testing, compression stockings, and some food limitations, she was still confused about all the “big words” and scared about getting another deep vein thrombosis, or DVT. A **Stop The Clot**® support group’s purpose is to help people in Melissa’s shoes.*

### **National Blood Clot Alliance (NBCA) Mission**

NBCA is a nationwide patient led advocacy group. Its mission is to prevent, diagnose and treat blood clots and clotting disorders through research, education, support and advocacy.

National Blood Clot Alliance believes:

- patient advocacy and education lead to improved health outcomes and quality of care
- patients and family members benefit from access to quality health care
- patients and family members benefit from information and research on blood clots and clotting disorders
- information and group support enhance quality of life

### **Purpose of this Guide**

NBCA sees the benefit of support groups led by peers and recognizes the need for skilled leaders. NBCA developed this **Stop The Clot**® (STC) Leader’s Guide to aid leaders in fulfilling the role.

NBCA thanks you for agreeing to lead an STC support group and values your time and commitment. Your work helps improve the awareness and quality of life of patients with blood clots or clotting disorders or those at risk for clots. This guide outlines how to start and/or lead a support group. It describes how to form a group and create a nurturing and supportive environment. It also provides tips on how to manage group discussion, and respond to any conflict or other challenges.

### **Need for Support Groups**

Blood clots and clotting disorders typically make an impact on the person with a clot, as well as those in their immediate circle, primarily family members and friends.

It is estimated that between 350,000 and 600,000 Americans develop DVT/PE each year. At least 100,000 deaths per year are thought to be related to these diseases. Most of these lives could be saved if more patients and healthcare providers were aware of the risks, symptoms and treatment of blood clots.

Treatment with blood thinners carries the benefit of clot prevention and the risk of bleeding. Individuals who had a DVT/PE may have reduced quality of life or feel that they are a burden to others, especially when DVT/PE becomes a chronic condition with personal and financial cost, such as when a complication like post-thrombotic syndrome leads to disability.

### **STC Support Group Goals**

STC support groups will discuss how to reduce the risk of forming blood clots, how to safely treat with blood thinners, as well as how best to use the healthcare system. This includes effective care among all providers, education/information, decision-making and self-care. Face-to-face and online support groups with such goals can help improve quality of life and/or coping. Support groups give patients a sense of control over their care and decisions about it. Participants gain increased knowledge from speakers, and other patients. Confidence in dealing with a blood clot increases when group members share similar problems. Patients and families find groups safe and supportive, which helps them deal with living with clots or clotting disorders.

As successes and failures are shared, group members may grow closer to one another. Members typically experience many benefits from giving and receiving help from each other, and usually become more comfortable asking for help.

Support group members need accurate, up-to-date information about blood clots and clotting disorders, on risk, prevention, and treatment. STC support groups provide a safe place to learn about these issues, including how best to talk with one's doctor, cope with stress and disability, and utilize community resources. Guest speakers are invited to some meetings to talk topics of interest chosen by each support group. Each group decides what is important, according to the unique needs of members.

Support groups are open to any person with a history of a blood clot or clotting



disorder, as well as any family member or close friend of an affected person. There is no charge or pre-registration. STC support groups are conducted openly.

NBCA sponsors support groups to:

- Foster an open discussion of how blood clots affect one's life
- Provide current, up-to-date information on blood clots and clotting disorders
- Support the group's leader in group oversight

## SUPPORT GROUP OVERVIEW

### Purpose and Description of a Support Group

The purpose of a support group for people affected by blood clots and clotting disorders is to provide emotional, psychological and moral support for members in a supportive, non-threatening environment. Each group is meant to be a self-help group, in which members share information, support and experiences.

An STC Support Group <u>IS</u> :	An STC Support Group <u>IS NOT</u> :
<ul style="list-style-type: none"> <li>• people living with blood clots or clotting disorders, who gather periodically with fellow patients and their families and friends to discuss common concerns.</li> <li>• a safe place for people to learn, share, obtain support and help others where individual differences are respected and confidentiality is required.</li> </ul>	<ul style="list-style-type: none"> <li>• professional counseling or therapy. When the group leader or members think that someone needs more help than a support group, they should suggest that the member think about a referral to a professional counselor or psychologist.</li> <li>• a cure for blood clots or clotting disorders, but it CAN help a group member cope with them</li> <li>• for everybody with a blood clot. Some people can't physically attend, some people prefer one-to-one relationships and some people just aren't ready to join or participate in a group.</li> <li>• a place to impose religious beliefs on others.</li> </ul>

## Leader Guidelines

The Leader:

- emphasizes that confidentiality is basic in any support group. NBCA requires that each prospective group member will respect and maintain the confidentiality of the group. Each member agrees not to repeat what is discussed in each support group session, and promises not to disclose the names of other members to people outside the group.
- makes sure that each group member signs a confidentiality agreement at the first meeting the member attends. (See Appendix A).
- helps group to set its own ground rules.
- makes clear that all medical treatment is ordered only by an individual group member's physician. Prescriptive advice is not given in support groups.
- states that a support group does not replace the services of doctors, counselors and other healthcare professionals.
- points out that each member of the group is responsible for group progress and connection, and each member of the group can participate or be silent to the degree that s/he chooses or that matches his or her comfort level.
- makes sure that the family and friends who make up a member's support system are welcome in a support group, and talk about how clotting affects them.
- stresses that STC support groups are not venues for selling or promoting any products.
- acknowledges that a participant may find that the group format does not meet his or her needs. Each group develops its own personality. The leader reminds the group to be aware of this, and suggests that members attend at least one other meeting before deciding that the group is not for them.
- remembers that members of groups may leave or change to another group for individual and sometimes unclear reasons, and not see this as a personal insult or statement about the leader or group effectiveness. The overall goal is for each member to benefit for the length of time s/he sees fit.
- offers a feedback opportunity to anyone who decides to leave, to get information that might help the group in the future.

## STARTING A SUPPORT GROUP

An STC support group can be started by a patient, caregiver or healthcare professional. The starter may not have the skills to facilitate a group, but can oversee the choice of an able leader, either a capable volunteer patient or healthcare professional.

### Starting a Support Group: Benefits and Skills

- **Time and energy.** It may save time finding information and give you energy from the support of others.
- **Organization.** The required skills are the basic ones you use to get through life. You must be able to plan a monthly calendar of meetings for the year, a sign-up sheet, and create and maintain an e-mail contact list (telephone or regular mail, if needed). You can delegate these tasks to other reliable volunteers, but must make sure they are done.
- **Ongoing commitment.** You can put boundaries on the time you commit. You can agree to lead the group for a limited time, usually a one-year minimum. It is best to find a replacement early, so that you have a smooth take-over. Your replacement should work closely with before your time draws to a close to pass the baton smoothly.
- **Not a one-person job.** You may be energetic and well-organized enough to get a support group off the ground, keep members inspired and delegate tasks or projects. However, group success depends on the commitment and connection of its members. Each group member should have some role or task, whether big or small.
- **Change your life.** You will no longer be able to be anonymous or silent about your experience with blood clots or clotting disorders, and you may become an advocate, spreading awareness about the public health threat associated with blood clots.

### Leader Responsibilities

- Find a suitable, accessible, and safe no-cost meeting space.
- Arrange the room to ensure adequate seating.
- Provide some plan for refreshments, and set up a schedule to share this task among group members, or decide that each person brings his or her own.
- Inform NBCA of meeting time, dates and place, and schedule meetings several months ahead of time.

- Promote and publicize support group meetings in local/neighborhood newspapers, electronic and social media, community centers, healthcare providers, etc.
- Contact potential new members in the area who have requested support group information.
- Lead group decision-making about meeting time, format, discussion topics and/or speakers to plan future meetings and to fill member preferences.
- Guide discussion and keep group interaction flowing during meetings.
- Distribute information on blood clots and clotting disorders to group members in collaboration with NBCA and local medical resources.

### **What You Need for Success as a Leader**

**You need many skills.** First and foremost, you must be an excellent listener and talk in words that group members understand. Listening is vital, and people have two ears and one mouth for a reason. You are the link to smooth relationships, discussion and interaction among group members. You start discussions and guide the group by adding comments, questions, or suggestions. You pull together parts of a discussion to add meaning. You keep the group focused through a range of ideas, as well as relate current topics to any previous discussions.

You avoid giving stock answers and pass up any desire to lecture, put down, convince or persuade other group members to your particular point of view. Leaders do not make decisions for group members because groups as a whole have responsibility for their decisions, and each individual is responsible for his or her decisions.

**You lead, but don't act as if you are above group members.** If you act in a way that members view as superior or as if you know it all, this produces an uncomfortable atmosphere that may silence members, and limit the support and trust within the group. When you participate as an active and equal member and show deep respect for other members, you create an atmosphere of friendliness, support and cooperation.

**Leaders cannot please everyone.** You have some critical elements in your role as a leader, but you cannot be all things to all group members. When you prepare well and attend to detail, it helps you avoid most pitfalls, although you cannot anticipate every group need. Your job begins when you start the meeting.

Recognize problems and intervene calmly and specifically, and you will contribute to group success.

The following interpersonal strengths help promote effective communication for success in your role as group leader:

- **A strong sense of self.** This helps you roll with the punches and keep things in perspective, so you do not personalize any challenges.
- **A good listener.** Silence is golden. Avoid interruptions and let members finish thoughts.
- **Ability to express thoughts and ideas clearly.** Make your thoughts clear, and do so when you restate or reflect group members' thoughts, or review discussion. You might start by saying, "What I think I heard you say is....."
- **Ability to cope with emotions.** You may find that your self-control is tested at times. Acknowledge and discuss your emotions and those in the group. Express emotions and any frustration or anger in as positive or constructive a way as possible.
- **Willingness to be open with others.** Be "real" and open when you talk about yourself. You may lose group trust when the group senses any "phoniness." When you are open, it frees group members to become more open. This promotes smooth interpersonal relationships within a support group.

## Getting Ready

It takes at least 8 weeks to get a new support group off the ground. The following table lists steps and estimates of time for planning.

Time in Advance	Task
<b>8 weeks</b>	<ul style="list-style-type: none"> <li>• Find a co-leader, if desired.</li> <li>• Decide how to divide tasks.</li> </ul>
<b>6 weeks</b>	<ul style="list-style-type: none"> <li>• Find a safe location at no cost to hold meetings with accessible, free parking.</li> <li>• Consider churches, community centers, hospital venues, etc.</li> <li>• Visit the meeting place to make sure it is safe, well-lighted, private, accessible and appropriate.</li> </ul>
<b>5 weeks</b>	<ul style="list-style-type: none"> <li>• Decide on a topic for the first meeting.</li> <li>• Find a speaker as needed.</li> </ul>
<b>3-5 weeks</b>	<ul style="list-style-type: none"> <li>• Create a plan for promotion and publicity and have NBCA post it on <a href="http://www.stoptheclot.org">www.stoptheclot.org</a> and Facebook.</li> <li>• Ask local healthcare professionals to recommend the group to patients with clots.</li> <li>• Post announcements about the meeting in clinics, hospitals, libraries and other public places.</li> <li>• Use free community calendars and electronic and social media.</li> </ul>
<b>1 week</b>	<ul style="list-style-type: none"> <li>• Contact the person in charge of arranging the meeting space to confirm the date, start time and end time of the meeting.</li> <li>• Find out any specifics the host site wants followed and how to access the space.</li> <li>• Ask whether a key is necessary for access and whom to call if there is any problem at the scheduled time.</li> <li>• Contact speaker to confirm date, time and location, and give appropriate directions to the site.</li> </ul>

## **SUPPORT GROUP MEETING**

### **First Support Group Meeting: What to Expect**

The first meeting may likely be a small gathering, perhaps only a few people. You can accomplish a great deal regardless of turnout.

Begin the first meeting with introductions. Ask each person to introduce herself or himself. It is up to the individual to decide how much personal information s/he wishes to share. You might start the first meeting by asking each person the question, "What brings you to this meeting?" or, "What do you hope for by being a part of this support group?"

Ask group members to decide at the first meeting, or within the first few meetings, what they wish to do by coming together. It may be helpful to first discuss the group's goals and write them down.

### **Setting Ground Rules**

It helps to establish some ground rules. Encourage all group members to participate in setting any ground rules, because group members will own and respect the rules. Ask the members whether they want to print and distribute their ground rules.

Ground rules help group members decide on ways to interact with each other during each meeting. Be prepared to help the group decide new ground rules or review previous rules at the beginning of each meeting. The rules can be short and sweet. They are best when they are as simple as "treat each other with respect," "only one person speaks at a time," or "everyone has an equal voice." Start by talking about how best to decide the rules. Choices for group decision-making can include voting with majority rule, consensus, or a combination.



Typical Ground Rules For Meetings	
<ul style="list-style-type: none"> <li>• Attend as many meetings as possible and be on time.</li> <li>• Listen to and show respect for the opinions of others.</li> <li>• Turn off cell phones.</li> <li>• No texting.</li> <li>• One person speaks at a time.</li> <li>• No side-conversations or whispering.</li> <li>• Keep on track with topics and time frames.</li> <li>• Agree that the only stupid question is the one not asked.</li> </ul>	<ul style="list-style-type: none"> <li>• Give credit to whom it is due.</li> <li>• Stop any side-conversations.</li> </ul>

This list gives examples of rules; but it is up to each group to decide its own ground rules.

### **Meeting Structure and Format**

You help guide how to define how meetings will go at the outset. Groups should decide at the first meeting how to open any discussion, continue it, and end the discussion. This helps keep things consistent and makes members comfortable.

## Delegating

You cannot and should not try to do it all as the leader. It may seem simpler at the beginning to handle all the details. However, doing it all is the quickest way to burnout. Delegate! Ask for group volunteers to do tasks related to meetings. This is a list to give you ideas about what you can delegate:

- Plan and lead discussions (or a co-leader is desired)
- Plan program topics and speakers
- Bring refreshments (if desired)
- Prepare promotional flyers; distribute and/or reach out to media outlets
- Handle a petty cash fund (if desired)
- Contact NBCA as needed
- Send reminders to other group members for upcoming meetings (by e-mail or social media if members have access)
- Handle other correspondence for the group or be the phone/e-mail contact

Some members may not want to take on a "job," or any more responsibility in what is probably an already overwhelming life. Avoid putting pressure on anyone, but make it more enticing by setting a time limit, such as six months, or designating a back-up person or "buddy" to help. Ideally, group members share responsibilities more or less equally.

## Items to Plan Ahead

**Meeting Schedule.** Many support groups spend their first few meetings simply discussing common concerns to allow members the chance to get to know one another in a relatively "pressure-free" environment. Eventually, need for outside information surfaces. Many groups decide to plan a yearly meeting schedule and agenda to plan ahead for speakers, etc.

Publish or send your calendar electronically or by snail mail in advance to the extent possible. This helps members who like to plan ahead and makes publicity efforts more effective. A consistent meeting time is preferable, e.g., the second Tuesday of every month at 7:00 PM.

**Agenda Topics.** Advance planning meetings is optimal, because it allows time to plan topics and find and contact speakers. Consider different ways to address blood clots in: educational, supportive and psychosocial. Groups usually plan

several topics over the course of a year, sandwiched between discussion sessions. This schedule gives the group the opportunity to think about what a speaker said, and allows them to build discussions around speakers/topics. Each group's agenda is unique and is based on member interest, availability of speakers, etc.

### Guest Speakers

As soon as a speaker agrees to address your group, ask a volunteer from the group to confirm this in writing. Ask the same volunteer to contact the speaker again before the date, with some general information about the group and a list of no more than 10 questions from the group. This reminds busy professionals to prepare, and ensures the group will get the most out of the presentation. Ask the speaker what they need in terms of technical or audiovisual equipment such as a proxima, computer, slide projector or flip chart. Get written permission from the speaker beforehand if you want to videotape the presentation. Provide specific directions to the meeting site and a contact name and number to call in case there are any last minute problems.

Possible Speakers for STC Support Groups	
<ul style="list-style-type: none"> <li>• nutritionists</li> <li>• nurses or doctors</li> <li>• psychologists or counselors</li> <li>• pharmacists</li> <li>• attorneys</li> <li>• exercise physiologists</li> </ul>	<ul style="list-style-type: none"> <li>• social workers</li> <li>• occupational therapists</li> <li>• physical therapists</li> <li>• genetic counselors</li> <li>• friends or family members telling their stories</li> </ul>

Decide who will introduce the speaker. It is a smart to choose the member who contacts the speaker. Contact the speaker in advance to make certain that the introductory material is correct and acceptable. Tell this member to be ready to share the speaker's background information, keep track of the time and convey a sincere thank you on behalf of the group at the end of the presentation. Send a formal written thank you to the speaker soon after the meeting. Let everyone know what the time limit is and make sure the presenter and group keep to it. Keep a list of the questions sent to the speaker before the meeting, and make sure to ask them.

Some speakers may donate their time, but may expect monetary help with travel or lodging expenses if funds are available. Others may request an honorarium.

Sponsorship may be available from pharmaceutical companies for a speaker, learning materials, and refreshments. Acknowledge these contributions at the beginning of the program and in a formal thank you letter after it. Note that NBCA cannot co-brand or endorse specific commercial products or treatments. Your local doctor can give you the names of pharmaceutical representatives in your area. It is a smart tactic to add speakers to your group's mailing list. They may know other people to refer to your group as members or speakers, or they may want to attend a future meeting.

### **Potential Meeting Topics**

- Causes of clotting or clotting risk
- Inherited or acquired blood clotting disorders
- Risk, prevention, treatment and signs and symptoms of DVT/PE
- Complications of DVT/PE
- Women and blood clots
- Blood thinners: old and new
  - a. INR monitoring for warfarin
  - b. Benefits and risks of old and new blood thinners
  - c. Drug and herbal interactions
  - d. Food interactions
  - e. Treatment recommendations
- INR testing (purpose and at-home options)
- DVT recurrence
- Compression stockings
- Children and blood clots
- Cancer and blood clot risk
- Blood clot risk in hip and knee replacement
- Coping with blood clots
- How much anxiety is normal and when should I seek professional help?
- Challenges of adherence; how to get "back on track"
- Family support of patients
- Adopting a healthy lifestyle
- Advocating for yourself with physicians

### **How to Promote and Publicize**

Once your support group has a full calendar of topics and speakers, let people know about the group. Your members can provide "word of mouth" publicity. There are lots of opportunities to reach a wider audience in your community:

Distribute flyers locally at doctors' offices, medical facilities or other public buildings such as libraries or places of worship. Use a particular speaker or topic to draw new members. Include a short, descriptive paragraph on what to expect at the meeting, and make sure the flyer displays the words **Stop The Clot®** Support Group clearly, with the NBCA logo. Present meeting topics as questions because it stimulates curiosity, such as, "Do you ever feel overwhelmed or alone living with a blood clot?" Advertise in local newspapers, public access TV, Internet message boards devoted to blood clots and clotting disorders to get the word out. Use technology, since the reach of the Internet and social media is extensive. NBCA can post information on its web site and Facebook.

1. **Ask speakers if they have media contacts you can call.** These include the public relations department of their hospital or organization.
2. **Don't be shy about making follow-up phone calls to media contacts.** Be courteous and brief. You may be doing them a favor by increasing their awareness about the risk of blood clots for them to share with the public.
3. **Don't be discouraged.** Remember that all media and PR people are bombarded by press releases daily. They may become distracted, or you may be replaced by a "bigger" story. You've made the connection, and they may remember you for next time. Develop relationships with media contacts to make future publicity easier.

## Membership Ups and Downs

Groups often begin with just a few members, even though each group is different. You and other group members can continue to recruit more people over time. Even a well-attended group has its down times due to a number of factors, such as the health of group members, the loss or death of a member, work or family demands or a lapse in meetings due to weather.

At times, you may need to rejuvenate your support group. There are several approaches:

- Ask one member to volunteer to call a missing member and invite him or her back.
- Ask the group to send e-mail messages or notes to absent members to make sure they are okay, and to invite them back.
- Organize a lunch or dinner outing to a favorite restaurant.
- Renew your publicity efforts through local media.
- Partner with another local support group, especially one with a link to clotting risk, such as a cancer support group for ideas and suggestions.
- Remember it is okay, and even healthy, for the group to take a break occasionally. It may be renewing. Many groups build a break into their calendar, such as skipping summer meetings. They often are more eager, stronger and revitalized when they meet again. Change is a constant in the life of every group. You should expect change as part of any group. Encourage the group to talk about change. Don't be afraid to take a rest, if needed, to "regroup." You deserve it for all you give and do!

## LEADING GROUP DISCUSSION

Prepare for any upcoming discussion by investigating a topic and thinking it through before the meeting. Use any points or ideas from your preparation to connect to group members' experiences and ideas. Throw out a sharply defined question to get the group thinking. Guide the group through its answers. The art of leading group discussion lies in your ability to maintain focus on a topic while broadening or narrowing what is being discussed, as needed.

Pay attention to how the group is interacting. Explore the major issues of the session, and relate them to any previous discussion. You benefit the group when you pull together related parts of the discussion and summarize what has been said. Take time every 15 minutes or so to draw any loose ends together: "Let's see where we are going." Be accurate and balanced in your summary, and ask the group to comment on your summary. Call attention to any unanswered questions for future discussion or for future speakers. Inspire group members to continue future discussion through a skillful closing summary.

### Guidelines for Leader Effectiveness

- Focus the discussion so the group is aware of the specific topic. Guide the group back to the original line of discussion if members drift off topic.
- Clear up any confusion in the group about goals.
- Discuss ways to compromise when the group is deadlocked or in conflict.
- Reflect back to the group the verbal and non-verbal messages you are receiving.
- Support the right of others to speak, especially when they have seemingly unpopular or different points of view.
- View any member's negative behavior as a problem of the entire group.
- Check your perception about a particular issue by asking questions such as, "Am I right in saying that you feel or think...?"
- Present any opinion to the group as a member rather than as a leader. Make it clear that you are expressing your opinion in any discussion as a group member, not as the leader.
- Don't direct questions at a single group member by name, unless you see that an individual is shy about getting into the discussion: "Linda, what do you think of this idea?" Otherwise, "Let's have some discussion on this topic," or "What do the rest of you think about this idea?"

- Point out any overlooked part of discussion: "Nancy mentioned last week that she thinks ... What do you think of that?"
- Keep group spirits high. Encourage ease, informality and humor. Encourage fun.
- Keep any differences of opinion friendly, or agree to disagree.
- Listen with respect and appreciate all ideas. Stress what is important, and turn the discussion away from talk that is off topic.

### **How Best to Ask Questions**

#### **Questions to OPEN UP discussion:**

1. What do you think about this issue?
2. Describe your experience in dealing with this issue.
3. Would anyone care to offer suggestions on how to cope with this issue?

#### **Questions to FOCUS or NARROW the discussion:**

1. Where are we now?
2. Can I review what we discussed so far, and talk about the progress we made in this discussion?
3. Your comment is interesting, yet I wonder if it relates to this topic.

#### **Questions to BROADEN PARTICIPATION:**

1. Would others who haven't yet spoken like to add their ideas?
2. How do these ideas sound to those of you who may be silently thinking about them?
3. What other aspects of this issue can we explore?

#### **Questions to LIMIT PARTICIPATION (of an overactive participant):**

1. We appreciate your contribution, but let's now hear from some others. Would some of you who have not yet spoken care to add your opinion?
2. You have made several contributions to this discussion, and now I am wondering if someone else would like to voice ideas.
3. Can you hold the rest of your comments until others voice theirs?

#### **Questions to help the group MOVE ALONG:**

1. Does the group think we have spent enough time on this and benefit if we



- now move to another aspect of it?
2. Have we covered this issue enough to shift our attention to a different area?
  3. Would it be in the best interest of time to move on to the next topic?

**Questions to help the group EVALUATE itself:**

1. I wonder if any of you thinks that we are stuck on this point. How can we get unstuck?
2. Perhaps we should look at our original goal see how well we did in reaching it?
3. Now that we are nearing the end of this meeting, would anyone like to suggest ways to improve our next meeting?

**Questions to help the group REACH A DECISION:**

1. Do I hear agreement on this point? (leader then gives a brief summary of discussion).
2. Since we seem to be getting close to a decision, what will this decision mean?
3. What have we decided up to this point?

**Questions to CONTINUE an unfinished discussion:**

1. Who wants to review what we already covered, since we ran out of time on this issue at our last meeting?
2. What points should we take up at the next meeting, since we have not yet reached agreement at this one?
3. Who wants to make suggestions about what needs more discussion when we next meet?

**Challenges of Leading a Group**

The success of any support group depends greatly on the leader's ability to anticipate and cope with challenges. These challenges include, but are not limited to: managing differences, dealing with dysfunctional or disruptive behavior, coping with conflict among group members and evaluating the group's progress. There will always be conflict or differences in any group, no matter what your level of effectiveness is as a leader. Conflict can be very healthy, when it is handled in the right way. Stay attuned to the sources of conflict. This guide

has tips on how to identify manifestations of problem behaviors and how to help resolve conflict within your group.

Here are some possible sources of conflict:

### **1. Values Differences**

People have different moral, ideological, religious, or philosophical outlooks. These outlooks typically begin in early childhood and manifest in deep-rooted values about education, politics, and religious beliefs.

### **2. "Seeing" Things Differently**

When people look at an issue or situation, they tend to select information based on their own experience. They interpret what is happening or being discussed in a way that matches their past experiences and ingrained values. As a result, people filter all new experiences and interpret them in unique ways, so it is impossible for anyone to truly "see" the whole situation as it is. The issue is filled in by beliefs shaped by individual bias or experience.

People tend to think that others see things exactly as they do. This leads to misinterpretation and creates sources of conflict. Keep in mind that strong emotions such as anger, fear and frustration distort how an individual "sees," and can lead to a minor disagreement getting blown out of proportion.

### **3. Competing for Time or Attention**

Pressure or need to compete for attention or speaking time can incline group members to side with members who support their own goals or agenda. This is less likely to happen when goals are clear and specific, and reviewed as needed.

### **4. Status Conflict**

Even though all group members are equals, one person may be seen to have a higher status in the group (e.g., for being in the group for a longer period of time). This may lead to conflict within the group.

Watch for expressions of group conflict, such as when members:

- make nasty or hostile comments or have frequent "side" conversations.
- show little patience with one another.

- criticize the value or capability of the group.
- put down contributions or participation of certain members.
- resist or refuse compromise.
- ignore or rebut the leader's suggestions.
- cut one another off before a point is finished.
- make subtle or obvious personal attacks.
- make it impossible to reach agreement.
- blame each other for "not getting the point."

### **How to Keep a Meeting on Track**

Prepare well and recognize when to interrupt to keep things running smoothly. When you interrupt or intervene as leader, focus the participants on the discussion to keep group interactions on an even keel.

Refer back to or reinforce the ground rules determined by the group. As a first step, this is likely to be the least threatening to the individual or group. As leader, your role is to support group members in achieving their desired goals. Intervene clearly and firmly, and match it with a supportive tone of voice and open body language, such as leaning toward the group.

The following are specific suggestions to intervene in the most common situations to keep support group members on track.

- Side-bar conversations
- Staying on time
- Never-ending discussion
- Conflict (personal attacks)
- Returning from breaks

<b>Side-Bar Conversations</b>	
<b>Situation</b>	<b>Specific Suggestions</b>
<p>A member of the group is having side-bar conversations with other participants while one member is talking or someone is presenting.</p>	<p>Try a friendly reminder: "Just a reminder, we agreed to one conversation at a time in our ground rules."</p> <p>Repeat the reminder. Make eye contact (with offending group member by name) and restate, "One conversation at a time please."</p> <p>Direct person by name "(Name), do you have a question or comment?" or "(Name), I can see that you have something to contribute; when (Name of speaker) has finished, we would love to hear from you."</p> <p>Make a direct request: "(Name), please hold your comments until (Name of speaker) has finished."</p>
<p>One group member is interrupting or having side conversations.</p>	<p>Talk to him or her one-on-one at break.</p>
<p>More than one group member is interrupting or having side conversations.</p>	<p>Put the process on hold and ask the group, "Can we hear what each one wants to say in some order?" or, "What are you discussing that you can contribute to the group?"</p>

Staying on Time	
Situation	Specific Suggestions
The group sets a lot to cover, but they seem to veer onto other topics.	<ol style="list-style-type: none"> <li>1. Remind the group that there is a ground rule to “keep focused.” Suggest using a <i>parking lot</i> to capture items that need to be pursued, but are not the focal points for this meeting. (See note on parking lots.)</li> <li>2. Refocus on the particular topic/agenda item: “I’d like to remind you that we are discussing (name topic). Please hold any other discussion until after we finish this topic.”</li> </ol>
Discussion continues for some time and the allotted time is nearly over.	<ol style="list-style-type: none"> <li>1. Close the discussion: “Group, we have 10 minutes remaining for this topic. What do we still want to discuss?” or “We are almost out of time for this item, and there appears to be more discussion required. Is that true?”</li> <li>2. Follow any Yes with, “What do you need to finish discussing this topic?” or “Why are we unable to close this discussion?”</li> </ol>
Item is truly important and wasn’t given sufficient time for the necessary discussion and action.	<ol style="list-style-type: none"> <li>1. Give participants a choice on how they spend their meeting time: “Is this topic more important than the remaining items for discussion, and, if so, when does the group want to discuss the other topics?” Note: Avoid extending meeting time to cover all items.</li> </ol>

**Note:** Suggest “parking the issue” if some group members are reacting to what is being discussed and go on to other topics. Move onto other topics after the speaker or topic discussion ends. You can make a “parking lot” on a flip chart, white board or note pad.



Never-ending Discussion	
Situation	Specific Suggestions
<p><b>Discussion Barriers</b></p> <p>There are times when a discussion does not come to a close, usually due to insufficient, inaccurate or unreliable information. There are also times when a topic provokes strong emotional reactions.</p>	<p>Follow the guidelines under “Staying on Time.” When there is insufficient information to make progress, group members should consider parking the topic for another meeting. If the rest of the meeting is dependent on completing any discussion, reschedule the meeting with a plan to assign participants to get unfinished or required information for the next meeting.</p>
<p><b>Personal Agenda</b></p> <p>This happens when a group member recounts the same story s/he told many times. You will likely notice this on the faces of the other participants (look for rolling eyes). A member who repeats stories may be unaware of the reactions of others. Such repetition can mask a person’s reluctance to open up to the group, and protects him or her from doing so.</p>	<p>Interrupt the story in a gentle tone when you notice this, especially when what s/he is saying does not contribute to or relate to the discussion. “(Name of repetitious storyteller), excuse my interruption, but I’m not sure how this fits with our topic. Can you clarify its value to the group?” Consider a gentle question about the person’s emotional response to the topic; it might open the person and shift the discussion to a different and more productive plane.</p> <p>Make eye contact with the repeater (Name) and say, “Your point sounds familiar. Is there a recurring theme in your story or am I missing your point?” Make eye contact with the other group members, who may use peer pressure. Ask (Name) what key piece of the discussion s/he wants to make and move on.</p> <p>Relate request to parking lot, as appropriate: “(Name), we agreed that this item would remain parked in the parking lot (or that it is off-topic).</p>



Never-ending Discussion	
Situation	Specific Suggestions
There are times when a group member continues to raise an issue, despite attempts to refocus.	Restate the request in a firmer tone. You can restate the interventions above, without using up valuable time.
There are infrequent times when a group member will persist.	Talk to him or her privately during the break. Be clear, yet gentle and ask for feedback about what s/he thinks is the effect of his or her behavior on the group. Ask for his or her help in moving the discussion forward.

Conflict (Personal Attacks)	
Situation	Specific Suggestions
<p><b>Individual Attacked</b></p> <p>A group member takes “pot shots” at another group member.</p>	<p>Try humor first. Ignore a first “pot shot,” unless you think it was deliberately nasty, or make light of any first offense with a remark such as: “I hope that comment isn’t an indication that we need armor for members of this support group.” If you don’t know the group or the “pot shot” thrower well, watch the reaction of the “pot shot” taker and the “pot shot” thrower’s attitude and body language.</p>
<p>The same group member repeats a “pot shot.”</p>	<p>Remind the group about any ground rule that mentions treating other members with respect. Make eye contact with “pot shot” thrower, and say, _____ (fill in the blank and state the ground rule).</p>



<p>The same group member ignores ground rules and continues to offend one or more members.</p>	<p>Deal with a repeat “offender” directly. Use firm words and keep a supportive tone. “(Name), you continue to break the ground rule about treating other members with respect. Please stop.” Interrupt and ask him or her, “What is your real concern here with this issue/idea? What suggestions do you have to improve the discussion?”</p>
<p>The “offending” group member persists.</p>	<p>Use a gentle warning: “(Name of repeat “offender”), despite my reminders, you continue to break group ground rules. If the two (or more) of you have a personal disagreement, this is not the place to bring it. How able are you to continue in this support group without making negative comments? What do you want to air so the group can continue? This gives the “offender” an opportunity to bow out of the group. If s/he chooses to leave, ask the support group their thoughts and feelings about continuing without him or her. Another choice is to ask these questions one-on-one with the “offender” during the break.</p>
<p><b>Group Attacked</b> A group member takes “pot shots” at more than one group member.</p>	<p>Use the same suggestions for someone who is taking “pot shots” at individual members.</p>



<b>Returning from Breaks</b>	
<b>Situation</b>	<b>Intervention</b>
<p>Support group members are late returning from breaks.</p>	<p>Start with a light tone by suggesting that group members synchronize their watches at the beginning of any break. Give a gentle reminder: "You agreed to return from breaks on time as one of our ground rules." Restate the scheduled time.</p>
<p>Support group members are consistently late returning from breaks.</p>	<p>Ask the group: "Out of curiosity, what is the reason you have a ground rule that says return from breaks on time, yet several people are late returning from break each time? What do we need to do to keep to our ground rule about being on time?" Start a discussion about ground rule and expectations. Ask how to keep breaks timely – is there a need for more breaks, are they too short or do members need flexibility from time to time to accommodate other needs? State times for breaks at the beginning of each meeting.</p>

## CONCLUSION

NBCA thanks you for your commitment to becoming a **Stop The Clot®** support group leader. Your role as a leader can help make a difference in the lives of people affected by blood clots and clotting disorders. You provide people with needed connection, sound information, and support. NBCA is grateful for your contribution and wants feedback on your experience as a leader as well as how the group progresses. Please contact NBCA at [www.stoptheclot.org](http://www.stoptheclot.org) if you have any questions.

NBCA also wishes to thank the following individuals for editing the Leader's Guide.

**Editor: (1st Edition)** Sharon Farsht Torodor, MPH

**Editors: (2nd Edition)** Kathleen Hynes (Volunteer) Mary Ellen McCann, RN MA

**Formatting:**

**Graphic Designer?**

## APPENDICES: RECORDKEEPING



Appendix A

### STOP THE CLOT®

#### CONFIDENTIALITY AGREEMENT

#### SUPPORT GROUPS

I have been informed of the need to protect the confidentiality of all personal information shared during **Stop The Clot®** Support Group meetings. This means that I will not disclose the names of the other members in the group or any specific information shared by support group participants. I realize that this is essential to develop trust among group members.

I understand that not only is this right of confidentiality granted to individuals under state and federal confidentiality laws, but that **Stop The Clot®** participants need to be able to feel comfortable sharing information in order to achieve support group goals.

I agree to maintain the confidentiality of personal and medical information shared by participants of the **Stop The Clot®** Support Groups.

---

Name

---

Date

---

Signature



**STOP THE CLOT®**

**SUPPORT GROUP REGISTRATION**

PLEASE PRINT CLEARLY

NAME	ADDRESS	PHONE	E-MAIL



## HELPFUL WEB SITES

- <http://www.stoptheclot.org/>
- <http://familydoctor.org/online/famdocen/home/seniors/common-older/800.html>
- [www.medicinenet.com/deep\\_vein\\_thrombosis/index.htm](http://www.medicinenet.com/deep_vein_thrombosis/index.htm)
- [www.nlm.nih.gov/medlineplus/ency/article/000156.htm](http://www.nlm.nih.gov/medlineplus/ency/article/000156.htm)
- [www.NATFonline.org](http://www.NATFonline.org)
- [www.Clotcare.com](http://www.Clotcare.com)
- [www.Preventdvt.org](http://www.Preventdvt.org)
- [www.FVLeiden.org](http://www.FVLeiden.org)
- [www.VDF.org](http://www.VDF.org)
- [www.APSFA.org](http://www.APSFA.org)
- [www.ACforum.org](http://www.ACforum.org)