

# SUPPORT GROUP MANUAL



amputee  
coalition™

Amputee Coalition

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## **About the Amputee Coalition**

The Amputee Coalition is an organization that brings together amputees, their caregivers and healthcare professionals for the common goal of education and support.

As one of the benefits of being in the Support Group Network, you are receiving this Support Group Manual. Other benefits include:

- Ten copies of the bimonthly *inMotion* magazine
- Five copies of *First Step*
- Five copies of the guide to *Insurance Coverage & Reimbursement*
- Complete contact info listed on Amputee Coalition Web site
- Registration at no charge for an all-day Support Group Leaders Summit, held at the Amputee Coalition National Conference
- Support group connections nationwide
- Access to monthly support group leader conference calls
- Knowledgeable staff to answer questions.

The Amputee Coalition and its Support Group Network have an informal relationship. Support groups function completely independently of the Amputee Coalition. And yet – this is a mutually beneficial relationship.

The Amputee Coalition depends on support groups across the country to help fulfill its mission to reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention.

When the Amputee Coalition receives calls from new amputees, or from their family members, or from a parent who's just given birth to a child with limb difference, we can put these people in touch with those who can best understand their situations, someone with a similar experience: a peer. Nothing else can take the place of peer support.

Support groups look to the Amputee Coalition to give their group members access to comprehensive materials and valuable services, including its award-winning publications and Peer Visitor Program.

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## **Keep the Amputee Coalition Informed**

The Amputee Coalition would like to hear from you. Please add the Coalition to your mailing list to receive your newsletters. Fax, mail or email the Coalition your event notices, ideas, article suggestions, and article contributions and photos.

Also, please keep the Coalition informed of any changes in your support group, such as time or location of meetings and contact changes, so that these can be updated on the Amputee Coalition Web site. Keep the Coalition informed by sending your information to [peersupport@amputee-coalition.org](mailto:peersupport@amputee-coalition.org).

## **Encouraging Individuals to Become “Friends”**

Thank you for contributing to the support of the Amputee Coalition’s mission. The Coalition now asks you to introduce your group participants to become “Friends” of the Amputee Coalition. In addition to the personal benefits that an individual receives, their support also helps support the Amputee Coalition in carrying out its mission:

- To support valuable programs that improve the lives of people with limb loss and their families
- To assist in the Coalition’s efforts to reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy.

Let your group participants know that when they become “Friends” of the Amputee Coalition they also:

- Help compile valuable data for the Coalition’s work with the Administration for Community Living (ACL) to document the need for ongoing attention and funding of programs for the amputee community
- Become part of an important group from which to collect survey information pertaining to the problems and needs of the amputee community (unless they opt not to participate in surveys)
- Belong to the community that can help the Amputee Coalition evaluate its work and learn what changes can be made to improve it.

## **The Power of Peer Support**

Support from one’s own peers in the wake of a life-altering event – such as amputation or the birth of a child with limb difference – is an invaluable part of the recovery process. While the medical community tends to think of this intervention as limited to emotional recovery, its power extends well into informational or educational aspects. A solid emotional recovery further empowers an individual along the path of physical recovery.

**Peer support** can be in the form of visitation from a trained and certified peer or in the form of a support group.

Immediately before or after amputation surgery, or the birth of a child with limb difference, peer support is essential. It is a service that has the potential to reach an individual on a level that no friend, family or any professional can touch and can jumpstart their transition to a new life.

Support groups provide an extension of peer support into a community of “others like me.” The social advantages of support groups are inherent in the structure itself. Any time a group of individuals come together around a shared life experience, there is immediately “common ground” between them, a bridge of understanding that no others can really provide. Support groups also offer an opportunity to reestablish a sense of belonging to a community.

To completely heal from such trauma clearly takes time. But time alone is not enough. There are many amputees who “recover” so fully that they will tell you they feel they have become more than they ever were before. To reside in this full state of living – which the Amputee Coalition has termed “thriving” – means that one must have been able to restore a sense of wholeness again. If we feel a sense of such completeness within ourselves, no matter where we go, we do not feel isolated from others. Wherever we are, we can feel we “belong.”

Achieving this experience of “belonging” is most readily accomplished through a membership with like kind, as if part of an exclusive club. A new sense of identity forms more easily through a mirroring with others like us, a reflection of complete understanding and acceptance. Nothing can surpass the “power of peer support” for the profound relief of feeling completely understood.

A unique opportunity for peer support in the amputee community can be found at the Amputee Coalition National Conference. This includes the exhilaration of being part of an actual majority, an experience that simply cannot happen anywhere else.

### **Program Topics and Speaker Resources**

Offering special programs with guest speakers during some of your meetings is beneficial in getting members enthused and avoiding the monotony of a format with only open discussion. Other benefits include:

- Educating members on related issues
- Providing subject matter for group discussion
- Allowing breaks for the group leaders or moderators.

Before establishing a program schedule, survey your membership to determine their interests. Frequency of special programs should be dictated by the preferences of the membership. Programs at every meeting may inhibit some members’ sense of socialization, while not enough programs may cause some members to feel that the meetings are a bit stale.

Groups that meet monthly may consider establishing program meetings for three or four meetings during the calendar year. Remember to take into account the culture of your group and what programs have been successful in the past. Perhaps one meeting a year could be designated a planning meeting at which business aspects of the group are reviewed and discussion takes place regarding annual goals and program topics. Program ideas can range widely, but in general, it is good for new groups to focus on amputee-related issues. Popular topics can be repeated annually or on a regular basis. Here is a list of potential topics:

#### **Prosthetic Issues**

- Fit and comfort tips and awareness
- Types of prosthetics
- Components of prosthetics
- Latest advancements in prosthetics
- Learning how to use prosthetics
- Costs and financial issues with prosthetics
- Medical problems related to prosthetics
- Skin conditions related to prosthetics
- Care and repair of a prosthesis

### **Medical Issues**

- General concerns for amputees
- Amputation-related pain
- Nontraditional medicine and treatment
- Foot care and diabetes
- Circulatory disease

### **Daily Living Issues**

- Assistive devices
- Emergency preparedness for people with disabilities
- Travel tips for people with disabilities
- Personal safety for amputees
- Home and vehicle adaptations

### **Sports and Recreation**

- Types and options
- Physical conditioning

### **Emotional Issues**

- Emotional recovery process
- Grief and depression tips and coping strategies
- Sexuality and disabilities
- Women's or men's issues

### **Legal Issues**

- Legal rights of amputees
- Dispute resolution
- Finding an attorney

### **Fun Programs**

- Humorous experiences of amputees
- Pets
- Hobbies

Generally, there are many professionals and groups in a community who would willingly lend their expertise and time for a group presentation. Develop a checklist for your program

arrangements. Make sure that your speakers know their timeframes and ask what audiovisual equipment they will need. Send them formal thank-you notes for sharing their time and expertise.

Examples of potential speakers:

- Doctors, prosthetists and other healthcare professionals
- Counselors/therapists
- Administrators of agencies serving people with disabilities
- Travel agents
- Athletes with limb loss/difference

### **Leadership Skills Roles, Responsibilities and Attributes**

The role of support group leader is both rewarding and challenging. You actually have taken on several roles and responsibilities requiring dedication and patience. The leader is the person everyone depends on to “get things done.” Your leadership challenge is to take “your” group and make it “theirs.”

Support group leaders should:

- Provide a safe environment for your group (physically and emotionally)
- Assist group members in setting goals and objectives to support your mission
- Provide accurate educational information and referral • Recruit group members to assist; assign roles and tasks
- Establish and maintain ground rules with a consensus of the membership
- Avoid giving advice or trying to solve problems for people; instead, facilitate the discussion and resolution of issues and problems.

Leadership is getting other people to follow you toward a common goal. A leader feels that he/she has something to offer or can make an existing situation better. Initiative and vision are the pillars of leadership.

### **Leading Versus Managing**

Leadership and management are different but not mutually exclusive. A person can be a leader without any formal managerial authority. Likewise, having managerial authority does not preclude being a good leader. So what's the difference?

A leader is someone who has the authority, patience and skill to guide people into action. Leaders should demonstrate the very traits they wish to foster in others – listening, advising when appropriate, sharing experience and perspective, encouraging exploration, consoling as needed, and showing respect.

A manager is a person with the knowledge, ability and authority to initiate action within an organization. Managers provide the environment and structure to ensure that the group operates efficiently and effectively. A good manager helps others to feel anchored and have a sense of belonging.

Support group leaders should understand the duality of their roles: managing people and fostering leadership that will keep the group motivated and growing.

## Delegating

Being able to delegate effectively is crucial to the long-term success of a support group. Tasks such as membership recruitment, marketing, programming, special events, newsletter and Web site maintenance are among the tasks that should be assigned to interested members. Delegation not only helps to get the job done, but also helps to develop committed members. Through effective delegation, leaders encourage team members to accept responsibility, think broadly about the needs of the group, and make decisions that achieve positive results.

Here are some tips for successful delegation:

- **Know people's interest and capabilities.** Delegate tasks to people who have an interest in the task or the qualifications to complete it. Understanding people's strengths, weaknesses, skills and ambitions will allow you to make effective matches between jobs and people.
- **Assign the task, not the process.** Define the desired outcome and let your team member determine how to complete the task.
- **Delegate the whole job to one person when possible.** Delegate smaller tasks to one person, as this fosters a sense of accomplishment for the person who completes it. Larger jobs may require a team of people.
- **Give enough information.** Provide enough information to the individual or team, so they know the full description of their duties and have a clear timeline for accomplishing the tasks.
- **Be on standby for help.** Be ready to provide help when the team member asks for it. Do not take over, but rather give the team member an opportunity to succeed and gain skill and experience.
- **Maintain control.** Know the status of the tasks delegated. Take corrective action when needed if the task is not proceeding well. Establish a timeline for the team member to report progress on the task.
- **Evaluate and reward.** Evaluate how well a task has been performed, as well as how well it was delegated. Praise is an important part of rewarding members who successfully accomplish a task.

## Managing Time

Effective time management comes naturally to some, while others struggle to keep up or be on time. Because being a group leader takes personal time away from family and friends, it's natural that stress will develop. Those who don't manage stress are prone to burn out. One of a support group leader's most important skills is balancing personal time against the needs and demands of the group.

People who practice time management function better even under intense pressure. Time management is as much about learning to become more efficient as it is about becoming more effective. It is said that efficiency is doing things right while effectiveness is doing the right things. Accomplishing both might take more practice, but the payoff is worth the effort.

Here are some valuable time management tips:

- **Leverage your time.** Recruit and use volunteers effectively. Manage through delegation.

- **Prioritize tasks.** Consider how much time a task will take and how valuable the results will be if carried out effectively. Determine priorities and create timelines. High priorities may need more advance planning and careful delegation than lower priorities.
- **Stop procrastinating.** Recognize when you've started procrastinating and find the motivation to actively manage your time. A common cause of procrastination is feeling overwhelmed by the task. Sometimes it is helpful to break a larger task into smaller ones in order to get motivated to tackle it.
- **Learn to say no.** Assess how the group's demands on your time fit with your personal priorities. There is a difference between being committed to the support group and wearing yourself out. Finding the strength to say "not this time" is ultimately your responsibility.

## **Facilitating**

As a support group leader, you will often play the role of discussion leader during group meetings. The dictionary describes "facilitate" as a way to "make something easier." A facilitator, then, is a person who makes group discussion easier. As with many other leadership skills, being a good facilitator comes with practice.

**Body language** – The facilitator's demeanor can set the tone for the discussion and sometimes for the whole meeting. A facilitator who is physically quiet, with a deadpan facial expression and a soft voice, will probably set a tone quite different from that of a facilitator who is physically active, is facially expressive, and speaks enthusiastically. The physical energy that is displayed by the facilitator is usually picked up and carried forth by the group. Even amputee support group leaders who have physical limitations can still strive to be as active and animated as possible. Nonverbal communications such as smiling, making eye contact and nodding in agreement all help to encourage energetic participation by group members. You also need to pay attention to the body language of your group members. Are they falling asleep, looking angry or tense, maintaining a distance from others, sitting rigidly, remaining silent, gesturing or showing emotional facial expressions? Verbal and nonverbal communication should complement each other. Because communication barriers and misunderstandings can arise from nonverbal communication, pay close attention to what your body language and that of your participants are saying.

**Listening and note-taking** – A good facilitator is an effective listener. In an open discussion, it is important to get everyone else's viewpoints first and add your perspective later. You need to understand in depth what the group members have to say, and use that learning to steer the discussion in a productive direction. You or someone else in the group should be taking notes for future reference.

**Getting the discussion started** – First, state the subject of the discussion and why it is important. Next, state any ground rules, such as individuals giving their names and a little background about themselves as they speak. If you know that your group members are generally bashful, perhaps call upon a known extrovert within the group to start off the discussion. Have some open-ended questions ready to keep the discussion moving if necessary.

***Keeping the discussion on track*** – The effective facilitator will remain constantly aware of the goals, and the ebb and flow of the discussion, as it either follows the proper direction or heads off on a tangent. While it is important to stay on track, you should not stifle the discussion by pushing it too aggressively. There is a delicate balance that requires some experience and finesse on the facilitator's part. Handling participants who want to dominate or who are simply unaware that they are babbling on and on is sometimes challenging. Try polite comments such as “That's a good point, Jim. Now let's see what others have to say.” Sometimes you may need to use a more assertive approach.

***Visual aids*** – With certain topics of discussion, such as those involving problem identification or brainstorming, use a flip chart or blackboard to list key points.

***Encouraging nonparticipants*** – The facilitator should remain aware of who is contributing and who is not. People who are not participating can be called on by name and asked for their ideas, but it's only safe to do this once. Some people find that speaking in public is so stressful they will avoid it at all costs. Insisting that they participate or calling on them more than once only increases their discomfort.

***Reinforcing*** – Remember: to keep the discussion flowing, people's comments should be reinforced. A “Thank you,” “Good idea!” or simply a smile and nod of the head can be reinforcing. Silence is not reinforcing. Criticism and judgmental comments are negative reinforcers.

***Handling extreme emotion*** – Sometimes a group member will break down crying in the middle of a comment. An empathetic comment such as, “I can see it really hurts you to talk about this,” is appropriate. You might also ask if that individual wishes to continue or if you should go on to someone else and come back to that person later. In extreme cases, you might call a short recess, during which you or another member can comfort the person privately. How well you handle such cases will impact others in the group. The appropriate impression to impart is that it's acceptable to have emotions, and it's OK to cry.

***Co-facilitators*** – Although a single facilitator is usually best, it is possible to have two if they are skilled and experienced in co-facilitating a group. In some cases, when you are facilitating a discussion involving complicated issues, you could appoint another person to observe and take notes. This has the added advantage of freeing you to listen more intently without having to capture the essence in writing.

***Ending the discussion*** – When it's time to end the discussion, summarize briefly the decisions or action items that resulted from the discussion, and thank everyone for their participation.

## **Ethical Issues**

As a support group leader, you may encounter situations that appear to be in conflict with your role in representing your group and its members. The following Q&A is designed to help you navigate those situations and address such concerns.

### **Endorsements**

**Q:** I was given a company T-shirt for free from my prosthetic company. Can I wear it anywhere I want?

**A:** Any endorsement-type item, whether purchased or given to you, should not be worn during activities with your support group. Endorsement is not limited to prosthetics technology and services only. Think about how the support group will be perceived by others you interact with as a representative of your group. For example, if you wear a shirt endorsing ABC Tax Services, this may lead someone to think your support group is endorsing them. As a formal leader, you should not wear or display any item/product that endorses anything.

**Q:** I work for a prosthetic company. Should I still be a support group leader?

**A:** Working for a prosthetic company, manufacturer or hospital while leading a support group might be challenging; however, it is not impossible. You must remain aware of situations in which your roles might cross. As a support group leader, no matter whom you work for, your role is to help empower your group members. You give them accurate information, but let them make their choices. If you have concerns about your dual roles, consider passing the leadership of the group to another group member who has both the interest and some leadership skills.

**Q:** When facilitating the group, I am almost always asked to talk about the prosthesis I use and the technologies I prefer. Can I talk openly about whom I go to and what I use for prosthetics?

**A:** It is important to always remain honest. However, it is equally important to use your skills as a group leader to refocus the group on the program or discussion. Remember that your purpose is to give people information and let them make the choice.

### **Donations/Fundraising**

**Q:** A prosthetic company gave a donation to the group during one of our fundraisers. Do I have an obligation to them?

**A:** The only obligation you have is to say, "Thank you." You can publicly acknowledge the donation, but that is as far as it needs to go. Many groups rely on donations and sponsorships, which is perfectly acceptable, but make it clear to the donor or sponsor that there should be nothing expected in return.

### **Confidentiality**

**Q:** A local prosthetist asked for our group mailing list to advertise a clinic. Most of our group would be really interested. Should I give him the list?

**A:** Absolutely not. This list is as confidential as the discussion during your group meeting. It should never be shared with anyone and should be well-protected with limited access. You can offer instead to let your group know about the clinic, or mail something on his or her behalf, asking for reimbursement of costs incurred.

**Q:** At the grocery store, I overheard two women discussing the Weight Watchers meeting they had attended the night before. They mentioned another participant by name and proceeded to discuss this person, mentioning how much she weighed. How can I prevent this from happening within the members of my support group?

**A:** First, you must be responsible for yourself. Make sure you practice what you preach and never share information about anyone in your group. Make it absolutely clear at each meeting that what happens in the group stays in the group. In fact, share this example to make it more personal. You must provide an atmosphere for your group members where they feel safe to share and have their privacy respected. You must adhere to this, as well as convey to the rest of the group the importance of confidentiality, perhaps having everyone sign a pledge of confidentiality.

### **Public Speaking**

Many people worry about speaking in public. It may be tempting to try and avoid public speaking, but as a support group leader, you will likely be in the position of leading, facilitating or presenting to your group or recruiting speakers for your group.

A successful presentation for yourself or outside speakers you may recruit for your group begins by becoming knowledgeable about the size and demographics of the audience, time allotted for the presentation, room set-up and audiovisual equipment needs. Your content should be developed with considerations as to what the audience wants to learn and what format the presentation will take. You'll need to determine how to organize the presentation, what your opening and closing remarks will be, and what questions you anticipate from the audience.

Also consider what supporting materials would be useful for handouts or display. Evaluate your presentation afterwards. If you present to an outside organization that provides an evaluation survey for its attendees, ask to see the responses about your presentation. Also, take into account your own comfort level during the presentation, and the number and types of questions the audience asked.

### **Fundraising Basics**

Groups may need to raise funds to publish a newsletter, invest in a media campaign or host a social event. Regardless of the reason, fundraising can also be a valuable way to unite members and give them a sense of ownership in the group. Support groups can realize their goals by drawing on individual member's contacts, skills and enthusiasm. In addition to raising the necessary funds for your group, fundraising projects and events are a great time to advertise the group's contribution to your community. Volunteers with strong commitments and successful track records for raising money know the best-kept secret to fundraising – to keep the fun in it!

However, you may also want to keep in mind the “80/20 rule” – that 80 percent of the work will be accomplished by 20 percent of the people. This also applies to fundraising for your support group. The brunt of the work often falls to the most involved members – those who are dedicated, willing to participate and able to sacrifice time and energy toward making the group's programs thrive.

To get members involved in fundraising, discuss the project at group meetings. Ask them to volunteer and accept responsibilities for segments of the project. Delegating tasks and responsibilities makes everyone's life a lot easier. Sharing the project makes it fun. Stress the importance of each person's participation in promoting fellowship and fostering a sense of accountability for the welfare of the group.

Where long-time members will sometimes have more resistance to a fundraising campaign, new members are often the ones who bring enthusiasm and the freshest ideas. If your group needs to be refreshed, you may find innovative ideas about how to best market, advertise or raise funds by turning to new members. People's varied backgrounds can turn up all kinds of talent and expertise.

Groups with nonprofit corporate status have the opportunity to apply for government or foundation grants, and are most likely to be successful with donors who restrict their giving to the local community that the support group serves.

### **The Amputee Coalition – Your Ongoing Resource**

Remember, the Amputee Coalition is your ongoing resource to help you lead a successful support group. Check the Web site for the most up-to-date information, tips, ideas and more. Learn what other support groups are doing and share your ideas with them and the Amputee Coalition.

We're here to listen and serve. Let us know what else we can do to assist you in your role as support group leader.

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