



**amputee
coalition™**

Starting a Support Group

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Table of Contents

About Support Groups	1
Types of Groups.....	1
• New Groups Versus Reforming Existing Groups.....	2
Launching a Support Group.....	2
• Find the Right People.....	2
• Establish the Integrity of the Group.....	2
• Have a Basic Plan	2
• Find a Meeting Place	3
Reaching and Retaining Volunteers.....	3
• So, How Do You Recruit Volunteers? And How Do You Keep Them?.....	3
• Determine What Type of Help You Need	3
• Extend Personal Invitations	3
• Acknowledge Efforts and Say “Thanks”	3
Program Topics and Speaker Resources.....	4
Fundraising Basics	4
Motivation.....	4
Fundraising Ideas	4
Leadership Skills.....	5
• What Is Leadership?	5
Next Steps to Success	5

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About Support Groups

Thank you for your interest in starting a support group. Just as starting a garden requires a few seeds, time and nourishment, a support group most often starts out with only a few individuals, sometimes even just one. These “seeds” have the dedication and desire to create and provide a forum for others seeking peer-to-peer support and education. A strong support network is an important part of adjusting to limb loss and can be an invaluable place for a new amputee to:

- Observe others who are successfully coping with limb loss
- Learn new coping strategies
- Practice skills in a supportive atmosphere.

Types of Groups

The form a support group takes can vary tremendously, but its role is universal. A good support group will provide its members with support, encouragement and useful information, in addition to being a social outlet. These are not mutually exclusive aspects, but rather a matrix of roles that ultimately foster a sense of well-being for its members. How a group originates has much to do with the type of group it becomes. Some individuals starting a group will logically try to create one that meets their own needs. Others try to address the needs of others based on what they imagine would have helped them earlier with their own adjustment. Support groups established through a facility such as a hospital or rehabilitation clinic may try to identify needs by collecting information from their patients and assigning a staff member to facilitate the group – at least in the beginning. Whatever form the start-up support group may take, chances are it will evolve over time, especially as members and leaders come and go. When a support group is no longer meeting members’ needs, they can simply leave the group, or they may decide to create a new one with a different goal. For example, a support group that remains focused on dealing with the issues of the new amputee may not suit someone who seeks support for getting back to a sport in which he or she used to engage. The key issue is about what constitutes a “peer” group, and that definition will change over the course of one’s recovery. This doesn’t mean members must always leave when their own personal focus changes. Many members choose to continue to “pay it back,” to offer the very support they received in the beginning to those still in the early stages of their recovery.

There are three basic types of support groups:

- Groups meeting face-to-face
- Online support groups
- Hybrid groups.

For some, just gathering with one another in a physical meeting space can be enough. For others, more formal educational opportunities are a welcome addition. Still others use the Internet through chat groups or discussion boards. These online forums can be an adjunct to face-to-face support, but they may also provide a sense of community, where a physical gathering may not be possible or appropriate, whether because of personal preference, geographic location or limited accessibility.

Hybrid groups, for lack of a better term, can be just about anything. Peers may choose to group around their own, or their child’s, specific level of amputation or cause of limb loss or difference. They may revolve around athletics, even a specific sport. They may opt to be simply opportunities for socializing, with such events as picnics or holiday parties. A unique opportunity for peer support for the amputee community can be found at

the Amputee Coalition National Conference and other regional events. This includes the exhilaration of being part of an actual majority, an experience that simply cannot happen anywhere else. (For more information about educational and support opportunities for your support group, please visit amputee-coalition.org.)

The information in this packet will focus on the face-to-face support group, which may or may not be legally incorporated. Since each state has specific laws governing nonprofit groups, you should contact your state attorney general's office or secretary's office for further information and/or resources. Additional advice also may be available through independent living centers, legal aid societies, volunteer accountants and attorneys and/or local chapters of nonprofit organizations such as the American Diabetes Association and the American Cancer Society.

New Groups Versus Reforming Existing Groups

Some groups will be totally new. Others may be a reformation or restructuring of a group that existed in the past but has disbanded. If you are resurrecting a group, you should take into account:

- Why the original group dissolved (e.g., low attendance, ineffective meetings, etc.)
- What type of structure the group had and where/how often it met
- What the leadership did or did not do to maintain the group
- Whether any previous leaders or members are interested in seeing the group reformed.

Launching a Support Group

Here are a few basic steps to launch your new group:

- Find the right people
- Establish the integrity of the group
- Have a basic plan
- Find a meeting place.

Find the Right People

Most support groups are formed by one or two dedicated people. You obviously have the initiative and willingness to help others, so use your enthusiasm to recruit other interested people.

Try seeking support from:

- Those who have experienced limb loss and their family members
- Prosthetists
- Hospital and rehabilitation professionals.

Establish the Integrity of the Group

If you are an individual amputee or parent of a child with limb difference, the group should not be formally identified with a hospital, prosthetic facility or rehabilitation center. You may accept space or supplies from them, but you cannot be seen as endorsing one practitioner or facility over another if you want referrals from the entire community. (Note: Support groups established by a facility, as part of their continuum of service to their patients, are an entirely different situation.)

Have a Basic Plan

Your group will be most likely to succeed if you:

- Understand your specific reasons for wanting to start a support group and outline a basic plan that addresses the needs of potential group members
- Determine if your group should address specific needs (such as parents of children with limb loss)
- Establish the type of meeting that best meets the group's needs by asking for input on meeting options, such as open discussion, social gatherings and formal speaker presentations
- Reach out to the Amputee Coalition for support group leader education and resources.

Find a Meeting Place

Look for free meeting space in your community (e.g., hospitals, churches, and senior or independent living centers). Remember to consider accessibility of the meeting place, including doorways, aisles in the meeting room, restrooms and parking.

Reaching and Retaining Volunteers

Looking at support groups across the nation, it is evident that one ingredient they have in common is volunteers. Active and dependable volunteers are the key to success for a support group program. Without volunteers, the best-designed programs and activities may never get past the planning stage. Volunteers can play a variety of roles, but each is vital to the success of the group.

So, how do you recruit volunteers? And how do you keep them?

Several essential actions should be taken to get volunteers and keep them satisfied:

- Determine what type of help you need
- Extend personal invitations
- Acknowledge efforts and say “thanks.”

Determine What Type of Help You Need

Reach out to other people affected by limb loss to help and to assist in determining what volunteer opportunities will be available.

Extend Personal Invitations

Most people volunteer because they are asked. For some, a general appeal for volunteers at a support group meeting or in a newsletter may be all it takes. If the same people are doing all the work in your group, step back and consider inviting someone new to assume specific responsibilities.

Acknowledge Efforts and Say “Thanks”

Volunteers will be most productive if they get satisfaction from their volunteer work. They deserve a return on their investment of time and effort and need to feel that they are contributing to the group and its purpose. No matter how large or small the tasks they perform, many people walk away from volunteer work, not because they find it too difficult, but because they do not feel their efforts make significant contributions.

Volunteers remain committed when they:

- Feel appreciated
- Recognize the significance of their contributions
- Receive recognition, both private and public.

Program Topics and Speaker Resources

If your group has had its first meeting and discussed the types of programming it would like to have, this list of potential topics will help you get started:

- Prosthetic issues
- Daily living issues
- Medical issues
- Sports and recreation
- Emotional issues
- Legal issues
- Fun programs of any type.

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 members' 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! Discuss the fundraising project at group meetings to encourage everyone's participation. People must know that they are needed and that their contribution is valuable. To get members involved in fundraising, 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.

Motivation

Incentives and tangible expressions of gratitude can also help spur and retain member participation. Gift certificates, plaques of appreciation and special prizes are just some of the many ways to demonstrate recognition of the importance of their contributions. A few dollars spent on incentives and inexpensive thank-you gifts also adds more fun to the project.

Of course, it is always important to select a fundraising project in which your group has enthusiasm and confidence in success. Members themselves should be interested in donating; otherwise, it is highly doubtful that the public will be.

Fundraising Ideas

Here are some suggestions for activities in which support groups can raise funds:

- Sponsor a golf tournament or sports event.
- Sponsor a walk.
- Hold a summer barbecue by asking supermarkets to donate meat and asking members to bring side dishes. Charge admission to the public.
- Host potlucks, pizza parties or ethnically themed dinners, and charge admission.
- Sell raffle tickets (if legal in your area) on homemade items (e.g., quilts, paintings or artwork).
- Host a candy dance or a chocolate fantasy, offering special chocolate desserts.
- Sell advertising space in your newsletters.

Leadership Skills

You may have heard the old saying: “Leaders are born, not made.” However, experts now believe that the ability to lead is not limited to the few born with exceptional talent. Even though an inborn potential doesn’t hurt, leadership is viewed as a set of skills that, with proper training, can be learned.

What Is Leadership?

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.

Attributes of a good leader include:

- Having a firm grasp on the material, a handful of appropriate skills and some relevant know-how
- Sharing knowledge with others in a productive way to direct the group toward its common goal
- Interacting well with the group and being in tune with people’s emotions, needs, obstacles and strong points
- Being receptive to others and creating an atmosphere of mutual respect that will help ensure the happiness and success of the group.

To be an effective leader takes vision, flexibility, knowledge, communication and hard work. Indeed, those who have the desire and determination to sharpen their wits, hone their skills and accentuate their virtue can deftly lead the group to success.

Next Steps to Success

We hope that the information in this packet gives you the tools needed to get your group organized and your meetings started. The Amputee Coalition is committed to supporting volunteers who give of their time to help others in their communities. Through our relationships with support group leaders across the country, the amputee community benefits from more options for support, education and the knowledge that they are not alone. Congratulations on this new journey. We are here to help and support you as a leader, and we look forward to building a relationship with you, your group and your community.

For further questions, please contact us at peersupport@amputee-coalition.org

or visit our Web site at amputee-coalition.org.