The original information below was made available from the National Spinal Cord Injury Association, however it is no longer found on their website. We thought it so relevant that we have reprinted it for you here.

HOW TO START SUPPORT OR DISCUSSION GROUP

We frequently receive calls for information on local support groups. Although there are thousands of people with all over the US, there are not always support groups for those that want them. Support groups provide a valuable service not only for counseling and support, but also for socializing and information sharing. "Old timers" have information to share with newer injuries, and groups have more influence with vendors or medical professionals to present information and products. If there is not a support group in the area, people frequently ask how they can start one in their area. The process of beginning a support group can initially seem daunting, however, it is easier if we break it into little pieces -- what I call the five P's:

Step One - People

After you have decided that you want to start a support group, identify two or three persons who share your interest in starting (not simply joining) a support group. Although it is possible to run a support group by yourself, you it is easier and you reduce the chance of burn-out if you have other people assisting you. If one of the people assisting you has a computer, that is an additional benefit, as they may be willing to maintain the mailing list, make flyers and print minutes and notices.

You also need to have an idea of how many people want a support group. Is there a group who have expressed an interest in meeting for support? Is there a concentration of people with SCI in one area? A feel for the demographics will affect not only who you have in the group, but where you meet and even what will be the group's emphasis.

Who can Attend You have to decide who can attend the meetings. Do you want the group to be only for people with SCI and spinal dysfunction, or can individuals with other disabilities attend. Another very important decision is whether you want the meeting to be only for people with disabilities, or also for family members and friends. Many times, people with disabilities will want a place where they can talk about their own issues without family around. Of course, family members have their own issues and they may want to speak about them without the person with a disability around. Possible solutions are to have 2 separate meetings, one for individuals with SCI, and one for family members. Another solution is to open the meeting to family members every 3 months. Of course, another option is not to include family members at all in the beginning phases of the support group.

Step Two - Planning

You will need to decide quite a number of things before the first meeting of your group, such as the frequency, location and emphasis of the group.

Decide how often your group will meet (NSCIA support groups must meet at least once a month.) If your group meets less often than once a month, it runs the risk of losing momentum and focus; interest may die out in the long weeks before the next meeting. Some groups may have the interest to meet more than once a month. If so, feel free to go with the interest, but don't feel that every two weeks is the norm. Many starting groups only meet once a month and are quite successful.

Decide how you will get the word out. Most people will have a list of people who would be interested in a SCI support or discussion group. A local rehab hospital may be willing to make a mailing to former SCI patients for you to advertise the meeting, but don't expect them to turn their list over to you. Many times a local hospital may also assist with mail and photocopying costs. Other places to advertise and solicit names are your local Independent Living Center (ILC), and with medical supply retailers. Don't overlook Vocational Rehabilitation. Remember, VR counselors are always seeing people with various disabilities, and are usually looking for ways to educate and train their clients. Don't forget to advertise in the local newspaper; most papers have a free section to advertise meeting notices.

What Kind of Group? There are many kind of support groups. Each has its own style, and each speaks to people in a different ways. You and the other people who are interested in starting a Support Group probably already have the type of support group you want in mind. Major types of support groups are as follows:

Peer Support groups. Groups led by others with similar disabilities. Usually these groups are not led by a professional like a social worker or rehab psychologist or counselor. A reasonable compromise might be a psychologist or counselor with a disability.

A professionally led support group. These groups are led or advised by a professional like a rehab psychologist, social worker or rehab counselor.

A discussion group. Not necessarily a support group, but a group with an educational emphasis to them. These groups may have a video or a speaker or topic each meeting. These groups may also provide a time where individuals can discuss issues of interest and concern to them to see if others have suggestions or have experienced a similar situation.

Step Three - Place

Decide on a central location. In many areas transportation is a major problem. A rehab hospital can provide a good location, as many people already know where it is, and you will have access to large meeting rooms as well as professionals interested in SCI. Some people may not feel comfortable meeting in a medical facility for personal reasons, so polling a few people about the location is wise. A private residence with a large room, or a clubhouse makes a good alternative, as

are church halls, Independent Living Centers, etc. The location should, of course be accessible, with plenty of parking and accessible via wheelchair accessible transportation if possible. Don't forget to make sure the bathrooms are accessible.

Some people may be tempted to have a rotating meeting place to make the meeting more accessible to people with transportation problems. This has benefits and potential problems. A benefit is that some people will have at least a few meetings in their area. This can increase the total number of people attending throughout the year. A potential problem is that the group becomes fragmented because only certain people attend certain meetings. Also, unless the meeting locations are well publicized in advance, people may forget where the meeting is and decide not to attend. With the same location, people always know where to go.

Step four - Publicity

Publicity is crucial to a beginning support group. It is important to leverage all available media (especially free outlets). For example:
Newspapers usually have a place to announce support meeting and clubs;
Radio stations do PSA (public service announcements). Make a special effort to try for stations that serve the population you want (usually young males)
TV and cable. Ditto on the PSAs, but also contact your local community access cable channel. Many cable channels have a scrolling marquee that announces meetings in the area. You may also be able to get air time on your local channel, since many of them are in need of programming.
Make up a flier announcing the meeting. You're not writing the great american nover here, so just give people the basics - date, location, time, and a brief description of the purpose of the group. Remember, if you're putting the flyer up in a public place you may have only 2-3 seconds to get a passerby's attention, so use large type and few words. Distribute the flyer to all the people on the mailing list. Try to make a personal visit to organizations like ILCs and hospitals so that you post the flyer yourself. If not, then print "Please Post" somewhere on the flyer. Again, ask Rehab Hospitals, ILCs, and other organizations and businesses to do a mailing for you.

Step five - Programming

So what will you do in your meetings? If your meeting is strictly a support group meeting, you will want to go around and check in with everyone and then begin the meeting using whatever model you choose. If your meetings will have an educational component to them, then planning the meetings will require additional effort. Topics for meetings include sports and recreation (vendors are a good source of information on the latest equipment), jobs and housing (ask a local ILC and/or your Voc. Rehab. department for a speaker), ADA training, etc. Your local rehab hospital is also an excellent resource for medical information, if members express a desire for that. Ask participants what they would like to hear about. The attendees are an excellent resource for information, each of us has special skills and insights on certain topics that others may be interested in.

There are also books, videos and movies dealing with disability, as well as mainstream materials that discuss or portray disabilities that can make good topics or jumping off points for discussion on disability. Fanlight Productions is an excellent (though pricey) source for specialty videos on disability. You can reach Fanlight at (800) 937-4113. Another activity that most people enjoy and which can generate enthusiasm in a group is to begin a peer visitation program or perform preventation and education programs at schools. We will cover these issues in a later issue.

Plan a time for people to just hangout either before or after the meeting, and make sure that people don't leave without signing up with their address and telephone number. Not only does this keep your mailing list up to date, but it also allows your support group to grow.

Running a meeting is learned skill, so don't feel discouraged if you're not perfect at it. It helps to have someone available who has done this before, so ask around.

This is not a comprehensive list of what to do, and running a support group is not easy, but it is a very rewarding and important service to the community. If you want additional information, feel free to call NSCIA. If your support wants additional information on becoming a part of the NSCIA Support Group Network, call and ask for the Support Group info packet.

This Factsheet is offered as an information service and is not intended to cover all treatments or research in the field, nor is it an endorsement of the methods mentioned herein. The National Spinal Cord Injury Resource Center (NSCIRC) provides information and referral on many subjects related to spinal cord injury. Contact the resource center at 1-800-962-9629.

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