

American Stroke
AssociationSM

A Division of American
Heart Association



Successful Stroke Support Groups

Our guide to organizing successful stroke support groups

The American Stroke Association is fighting back against stroke.

For more than 50 years, the American Heart Association has funded research to discover new ways to prevent and treat stroke. We have also developed programs and patient and professional education materials to raise public awareness about this deadly disease. And, in 1998, we created the American Stroke Association as a division of the American Heart Association to intensify our efforts on behalf of stroke survivors and caregivers. Our activities include:

- Teaching families the warning signs of stroke.
- Funding research to find new ways to prevent stroke.
- Developing guidelines for physicians to treat stroke.
- Providing stroke survivors and their families a place to get answers after stroke.

The American Stroke Association is a nationwide network of stroke survivors and caregivers sharing information, experience and support with anyone affected by stroke. The association also includes dedicated professionals from many different medical and research disciplines, all united to reduce disability and death from stroke.

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American Stroke Association

...A Nationwide Network of Stroke Families Helping Stroke Families

The American Stroke Association, a division of the American Heart Association, is dedicated to helping stroke survivors rebuild their lives. The American Stroke Association's Stroke Family Support Network is a clearinghouse of information about stroke prevention, treatment, rehabilitation and recovery. It helps consumers learn about stroke...what it is, where to go and what to expect after a stroke. Over 1,800 stroke groups and more than 36,000 individuals throughout the United States are part of the Stroke Family Support Network.

American Stroke Association partners bring hope and encouragement to the nearly 5 million stroke survivors in the United States through a wide variety of peer support and educational services. The primary network programs, services and activities are:

800 Stroke Family "Warmline"

A toll-free information and referral line (1-888-4-STROKE [1-888-478-7653]) helps families connect with other stroke survivors and caregivers to get tips on daily living and other peer information and support. Many of the Stroke Support Specialists answering the calls are also stroke survivors or caregivers.

Stroke Connection Magazine

This award-winning, 32-page, four-color, bimonthly health education and outreach magazine extends the voice of the American Stroke Association beyond the network of support groups. Information on stroke resources, caregiving, treatment advances, self-care strategies, coping skills and real-life experiences help stroke families and healthcare professionals throughout the nation.

Call 1-888-4-STROKE to receive a free copy or visit StrokeAssociation.org and sign up today.

National Stroke Group Registry

The American Stroke Association encourages the development of stroke support groups and provides resources for them. New stroke groups across the country are registered, offering many benefits to stroke group leaders, including referrals of potential new members, and *Stroke Connection Magazine* free for group members.

Patient Education Materials

The American Stroke Association offers magazines, fact sheets, brochures and other stroke-related information through the Stroke Family "Warmline," ***1-888-4-STROKE (1-888-478-7653)***.

American Stroke Association...help us help others help themselves. Share the American Stroke Association Stroke Family "Warmline."

Why Start a Stroke Support Group?

Living With Stroke: An Adjustment for the Family

Relationships often change drastically after someone has a stroke. Physical difficulties and the emotional problems a stroke can cause may quickly change how stroke survivors, their families and others get along.

Survivors often say friends and family members feel uncomfortable around them. “He just is not himself,” people say. Or, “She is not like she used to be.” The old circle of family and friends begins to disappear, and survivors say it’s hard to fit in like they did before.

After a stroke, even simple things like shopping, talking on the telephone or taking a walk may seem impossible. Talking or writing a letter may be too difficult for a stroke survivor who has problems using or understanding language. Something as common as going out to eat can be a major challenge. Survivors also may not be able to drive a car or use public transportation. Other day-to-day activities may become major obstacles to survivors.

Stroke affects more than the survivor. Family members can also be confused, frustrated and feel isolated. Relationships may become strained, especially when a family member becomes a caregiver. And the caregivers may get angry or feel guilty about their feelings toward the survivor, who is taking so much of their time and energy. Individual family members may have to adjust how they feel about themselves and others as responsibilities shift and family relationships change.

There are no easy answers to the problems a stroke can create. These changes can negatively affect the survivor’s rehabilitation and recovery after getting out of the hospital. The longer a stroke survivor is not in society, the harder it is to rejoin society again.

The Need for Peer Support, Hope and Encouragement

Stroke survivors and their family caregivers need help adjusting to the changes in their lives. That’s why many stroke survivors join support groups. Sharing similar problems helps survivors learn to live with the changes. Stroke support groups offer survivors, their caregivers and other family members chances to share concerns and support each other. They unite around their common experiences and find positive solutions.

Stroke support groups allow stroke survivors to help themselves and other survivors create meaningful lives after stroke. Coming together in an atmosphere of caring and cooperation, survivors, their family caregivers and friends can forge a new sense of community. New goals and friendships are started, renewing hope and encouraging independence.

A sense of empowerment is at the heart of a “self-help” or “mutual-help” group. It can motivate passive “patients” to become thriving survivors and create active new roles for themselves. Stroke creates many physical and emotional challenges. Each stroke survivor faces a unique set of disabilities and losses, and each copes with them in his or her own way. However, the warmth, acceptance and emotional support that a stroke support group offers can often be the key to uncovering the hidden strengths in many survivors.

Dealing With Your Isolation as a Caregiver

Peer support groups can be an important source of firsthand information. They may also be crucial for the caregiver's own well-being. They can...

- Help you learn more about your loved one's condition, including treatments, prognosis and what the future may hold.
- Provide information about the best community resources (including day-care centers, assisted-living services and home-care nursing), the most responsive professionals and the latest equipment.
- Create networking connections so you'll have access to the best care possible.
- Lessen the sense of stigma associated with being disabled.
- Give you an opportunity to joke and laugh about your circumstances with people who really understand and won't judge you.
- Give you an opportunity to cry and complain without others making you feel guilty about your own needs and pain.
- Give you a moment to focus on just you.
- Alleviate your aloneness by introducing you to new friends who understand.
- Help you brainstorm solutions to your problems.
- Relieve stress and help you feel more in control of your life.
- Give you hope as you listen to how others have coped in similar situations.

Source: Adapted from *Helping Yourself Help Others: A Book for Caregivers* by Rosalynn Carter ©1994.

Discovering the Value of Support

Social support is important in stroke recovery. Social isolation has been called a risk factor for a poor outcome after stroke. Family and friends provide important support for many survivors, but stroke support groups can also play a vital role in stroke recovery. They can decrease the isolation of both survivors and family, and introduce new friends to replace those often lost after the stroke.

Stroke survivors not only face new disabilities, but also possible medical complications and the need to prevent recurrent strokes. A stroke support group that empowers members with information and provides emotional support can promote both good health and a good quality of life.

When There Seems To Be No Hope

Chen's family was very worried about him. Ever since his severe stroke the month before, he had been acting very strange. He had aphasia and couldn't understand what people tried to tell him.

He seemed to have given up on trying to communicate. In fact, he just sort of shut down. He often cried, too, which wasn't at all like him.

Elaine, Chen's wife, and their grown sons knew this behavior was unusual and that it probably required professional help. First they discussed Chen's aphasia with his speech therapy specialist. They wanted to see what they could do to lessen Chen's frustrations.

"Just keep trying," Cheryl told them. "If talking doesn't seem to work, try pantomiming. Try using pictures to communicate. Be positive around him, too," she said, "but be yourselves. Reassure him and encourage him to stay relaxed. He's been through a big change, and it's going to take time for everyone to adjust."

Still, despite their efforts, Chen seemed to withdraw more and more. He began refusing to participate in his physical therapy exercises, too. The family spoke with Chen's physician next.

"I wanted to see if we could shake this without resorting to medications, but if Chen isn't participating in his physical therapy, that could just complicate his health down the road," Dr. Michaelson said thoughtfully. "We'll try this for a little while and see if it helps. I think if we can just get him through this, he'll be OK."

Dr. Michaelson put Chen on antidepressant medication and monitored him carefully. The family noticed that Chen's mood seemed to improve. He began to respond again to their efforts at communication. His speech and physical therapy began to show more progress, too.

The family was greatly relieved. Now they felt they were back on track. But they knew they had a lot to learn about stroke and depression. It was clear that Chen's illness had affected them, too. With Chen's agreement, the whole family joined a stroke support group. Every week they got together with other families that were experiencing the same things they were. It felt good to have a place where they could get their anger, fears, and confusion off their chests. The best part was being with other people who understood what they were going through.

Source: American Heart Association Family Guide to Stroke, ©1994, American Heart Association. Published by Times Books, a division of Random House, Inc., 1994.

Finding a Way To Help

Stroke families can't benefit from belonging to a support group if none exist in their community. You can help by organizing a new stroke support group in your community or strengthening an existing one.

There are many ways to start and sustain a stroke support group. What works for one group may not work for others, since members are unique. The purpose of these guidelines is to help you plan a group that fits the needs of your members.

Coming Back: You're Not Alone

My first source of information was the public library. I took out every book I could find, some of them twice, which gave me some answers to my questions. Then, fortunately, I heard about stroke groups. An announcement in the local paper invited anyone interested in such a group to a meeting at the library, and thus the Wright County Stroke Club was born. This fledgling group, with no funding and little support, was my ray of hope.

I knew that a stroke group could not make my husband less aphasic or more alert or stronger physically. But here were people — wonderful, caring, dear people — who understood what my problems were. They, too, were seeking to put the pieces of their lives together again. They, too, knew the joys of small successes, as well as the heartache of continued failures in the long journey to a more meaningful and normal life. We were not alone!

— An excerpt from "Odyssey" by Inez Thoren, Caregiver, Stroke Connection Magazine November/December 1983

How Are Stroke Support Groups Started?

Setting Goals

The purpose of a stroke support group is to provide stroke survivors and their family caregivers an opportunity to support each other as they strive to rebuild their lives and promote health, independence and well-being. Goals clarify what the group wants to accomplish. Consider these items as you develop the goals for your group:

- To provide accurate information for group education that promotes a better understanding of stroke recovery, rehabilitation and prevention of recurrent stroke.
- To offer a way for stroke survivors to meet others with similar challenges and experiences and provide mutual positive support.
- To renew hope and promote independence by offering opportunities for survivors to challenge themselves and continue to improve their performance of daily living activities.
- To provide caregivers and family members a structured way to share and support each other.
- To offer stroke families the resources and support they need to live an active and satisfying life while coping with their losses and disabilities due to stroke.

The goals of a stroke group should change as the group's membership and focus changes. Review the goals regularly and adapt or add to them. Here are some more ideas:

- To encourage and strengthen dignity and self-esteem by providing volunteer opportunities within the stroke group and the community.
- To educate people in the local community about stroke prevention and stroke disabilities.
- To reach out to new stroke survivors and their families by providing a support service such as the American Stroke Association's Peer Visitor Program.
- To improve communication and understanding among stroke families.
- To offer support uniquely designed to help stroke family caregivers.

- To encourage the active involvement of survivors with aphasia who have difficulty communicating in the group.
- To reach out to stroke survivors in communities without active stroke support groups.

Getting Organized

Starting a stroke support group takes a lot of work but can be very rewarding. It's extremely satisfying to help stroke families rebuild their lives. Sharing responsibilities makes getting organized easier and gives others a sense of ownership. Laying a strong foundation now will also have long-term benefits such as dedicated members, widespread publicity and committed leaders.

Contact stroke survivors, family members and stroke healthcare professionals for more guidance. When you talk to individuals or groups, tell them how group members can benefit from friendly, supportive, informal meetings. Once you find two or three interested people, you're ready to take the next steps for starting your group.

Organizing a new stroke group will be easier if you include these components:

- A key person (or two!)
- An advisor, group facilitator or healthcare professional
- A sponsoring agency
- A planning committee



Bright Ideas From Successful Groups

Some ingredients for a viable group...

- A capable planning committee
- Committed leader(s)
- A variety of interesting programs
- Capable volunteers
- Community recognition
- At least one sponsoring agency
- Good planning

Don't reinvent the wheel

If you are starting a support group, consider consulting with those who have done it before:

- See the helpful organizations listed in section VI of this guide.
- Call the American Stroke Association Stroke Family “Warmline” at 1-888-4-STROKE (1-888-478-7653) for advice.
- Visit another stroke support group in your community.
- Talk to leaders of other types of support groups in your area.

Finding Leaders and Facilitators

A **key person** (or two) is someone who has a prime interest in organizing a new stroke group. This person may be a stroke survivor, the caregiver of a stroke survivor, or a social worker or other healthcare professional from a rehabilitation center or community services agency. It's important for this person to be able to commit the time and effort needed. Whether the key person or the sponsoring agency comes first varies with the community. Typically, a need surfaces and the order follows logically. Direction may be needed, but a stroke support group will emerge.

The role of an **advisor or group facilitator** will vary with individual groups and as groups pass through different stages of development. An advisor can act as an advocate and consultant, especially while the group is forming. That role may shift to facilitator or guide as leaders emerge and the support aspects of the group become focused.

Both lay and healthcare professional facilitators can share their unique perspectives. However, the collective experience and knowledge of the group is more important than that of the facilitator. A good facilitator must be able to empower the members to support each other. That allows the internal leadership to thrive.

An advisor or facilitator should have a strong interest and ability to empathize with the problems resulting from a stroke, and have good group facilitating skills. Enlisting a qualified healthcare professional in this role can enrich the group with additional knowledge of stroke, rehabilitation and group process. A professional's contacts in the healthcare community can

help members generate support and referrals for the new group, and find speakers and other helpful resources.

If a sponsoring agency is found first, its staff may be able to recommend an advisor. The advisor's main duties are:

- To provide or be the liaison with the sponsoring agency.
- To help manage the group.
- To facilitate the process as the group develops programs, defines function, promotes leadership among members, and helps establish and carry out the group's goals.

Obtaining the commitment of a recognized organization can be very useful in helping the group reach its goals. A sponsoring agency can also help provide continuity as the group evolves and its membership changes. The agency could be the local office of a national organization, a hospital or rehabilitation center, or a community service group. Some possible organizations that may be interested in sponsoring a stroke support group include:

- American Stroke Association, a division of the American Heart Association
- Nursing homes
- Easter Seal Society
- Nurses associations
- Hospital rehabilitation departments
- YMCA and YWCA
- Community rehabilitation centers
- Outpatient clinic
- Speech and hearing associations
- Family service agencies
- Senior citizens' agencies
- Mental health groups

When you contact these organizations, ask if they sponsor a stroke support group or plan to start one. If there's an existing group, you may want to visit and ask them to partner with you to start a new group. A partnership like this lets you share valuable member resources.

A **sponsoring agency** may be able to provide some needed services — such as meeting space — and help with funds for refreshments and mailings. In addition, many services and staff of the sponsoring

agency may be available to help the group. Social workers, speech/language pathologists, occupational or physical therapists, and other healthcare specialists can advise or facilitate, or be involved occasionally as guest speakers.



Bright Ideas From Successful Groups

- Form a professional advisory council.
- Involve a multi-disciplinary group.
- Get people to work who are motivated by personal interest rather than a sense of duty.

Forming a planning committee of three to five members to plan the initial meeting and establish some basic ground rules and an organizational structure isn't necessary but can be very helpful. A planning committee can share responsibility and help prevent leader burnout. This fosters a sense of ownership among group members.

Forming a committee to guide your support group provides a way for members to be actively involved. It also establishes the group as a stronger entity in the community. Involving stroke survivors and caregivers on the committee is essential to assessing the needs accurately and setting appropriate goals.

Recruiting healthcare professionals for your committee can strengthen its credibility and also increase its visibility. Healthcare professionals are valuable to you for three reasons:

1. They know people who can present educational programs on stroke rehabilitation and mental health.
2. They meet stroke survivors daily who are potential group members.
3. Their knowledge of the community and stroke recovery and rehabilitation benefits your stroke support group.

A committee may also be helpful if your group plans to partner with community organizations, such as the local American Heart Association office.

How long should your committee serve? That's up to you. Some groups never disband their committee. Others use the committee until their support group has become stable.



Bright Ideas From Successful Groups

Groups may have difficulty in the developmental stage because they:

- Lack volunteers.
- Lack attention from coordinators and professionals.
- Fail to establish regular meeting times.

A survey of group leaders offered these solutions:

- Develop a better business base.
- Ensure adequate funding.
- Get better community support by sponsoring educational programs.

Next Steps

Once you have commitments from one or two key people, the next steps are to locate a sponsoring agency, a planning committee and an advisor or facilitator. Your nearest American Heart Association/American Stroke Association office may be able to help.

Here are some steps adapted from those used by the American Heart Association/American Stroke Association Texas Affiliate office. You can adapt these ideas to fit your group's needs.

- Review advantages of developing a stroke support group in your community with the stroke program committee of your nearest American Heart Association/American Stroke Association office.
- Ask the American Heart Association/American Stroke Association program committee about helping to organize a stroke support group and whether it would be a sponsoring organization. Review the advantages of involving other organizations to co-sponsor the group.
- Ask the American Heart Association/American Stroke Association program committee to help organize a stroke group planning committee made up of healthcare professionals (such as physicians, physical therapists, speech therapists, occupational therapists, rehab nurses, etc.); two or more stroke survivors and caregivers; and one or two other interested persons.

- Ask the planning committee to help locate a suitable advisor or facilitator for the stroke support group.
- The committee creates a list of sources for new members with the planning committee, including physicians, public health nurses, Visiting Nurses Association, rehabilitation hospitals and centers, VA hospitals, etc. Committee members will ask these individuals and organizations for stroke survivor referrals.
- The committee sends invitations announcing the first meeting of the stroke support group and publicizes the group.
- The committee may set the date and time for meetings, choose a stroke survivor to lead the meeting along with an advisor, and suggest a meeting location, types of programs and frequency of meetings.
- Before the first meeting, the temporary group leader and advisor will meet with the committee to develop a detailed meeting agenda. This group can also identify potential support group leaders.
- At the first meeting, the stroke support group leader and committee will present their ideas to the group. The members present at the initial meetings will decide how often to meet, the kinds of activities the support group will sponsor and where the group will meet. An acting stroke support group leader will be chosen if one hasn't been selected and how long the term leaders will serve will be decided.
- File a list of members and guidelines governing your group with your nearest American Heart Association/American Stroke Association. The local office may want to submit this list to the American Heart Association/American Stroke Association affiliate stroke group coordinator or the person at the state level with stroke responsibilities.
- Review your group's activities after six months and make any changes necessary.



Bright Ideas From Successful Groups

- Ensure that the core group responsible for organizing the new support group meets several times before the first official meeting.
 - Be realistic about what type of service you can provide.
 - Involve stroke survivors at the outset.
 - Visit another stroke support group.

Finding Members

Stroke support groups use different criteria for membership. In addition to stroke survivors, some groups include individuals with other medical conditions, such as head injury and other disabling conditions. Restricting membership to survivors of stroke or perhaps other types of brain injury keeps problems and challenges similar. This allows group members to more strongly identify with one another. Advocates of a broader membership believe that added diversity makes for a more interesting group.

Broad membership often attracts more members to the support group. Your group can include family members and friends of stroke survivors, or you can create a separate group for caregivers. You may want to experiment with your membership.

You'll probably attract enough people to your first few meetings. Over time you'll want to involve more people to keep attendance high. Aside from your personal contacts, some reliable sources for new support group members are physician referrals, healthcare professionals, public health agencies, social services and the ministry. Community publicity is another way to attract interested members and their families.

The first meeting is very important. Allow enough lead time for extensive publicity so information can be circulated. The first program should be well-planned, constructive and purposeful. It could feature a healthcare professional speaker on a topic dealing with the psychosocial aspects of stroke as it affects survivors and families. The speaker should be well-qualified and understand the goals of the group. Another option is to feature a stroke survivor who has made a successful adjustment to a

changed lifestyle after stroke and can give an inspiring presentation. The first program should also highlight these items:

- Purpose and goals of the stroke group
- Possible organizational structure
- Possible future programs
- Role of sponsoring agency, committee members and leaders
- Introductions of those attending with brief background information



Bright Ideas From Successful Groups

Choosing a name for your stroke group can help build group cohesiveness and a sense of identity. Names range from simple to elaborate: Bethesda Stroke Support Group to Stroke Victors, Rebounders, Speak-Easy, Different Strokes, and Victory Over Stroke. Your planning group can choose a name, or you can let your first group members take part in the selection. However you do it, make it a fun, light-hearted project.

Be sure that everyone who attends feels welcome. Use nametags and designate some committee members as “hosts.” Serving refreshments is a must!

Identifying a Meeting Place

How often and when you hold meetings is up to you. Groups meet weekly, every other week, monthly and even every other month. Monthly meetings are the most common. Afternoon and evening meetings are more popular than morning meetings, although some groups do host morning meetings. Most support groups meet on weekdays.

- Choose a convenient time for you and the two or three people working with you. Later, if members prefer, schedule meetings that are more convenient for the group.
- Most meetings last 1½ to 2 hours and offer programs and social time. Your meetings should be long enough to offer value and short enough to avoid being tiresome.
- Meeting in the same place eliminates confusion, so scout around to find a convenient location.

- Many meeting rooms are free. Personally inspect meeting facilities before you accept or reject them.
- Choose a safe, easily accessible location with ample parking. Notice restroom availability, noise level, lighting and ease of entry in the facility you’re considering. Policies regarding building hours, janitorial services and refreshments will play a big part in your choice. For instance, if you want to serve refreshments at your meetings, consider a meeting facility with a kitchen.
- A clean, cheerful meeting place with plenty of room to seat everyone will enhance the quality of your meetings. Possible locations include:

- Your local American Heart Association office
- Hospitals
- Rehabilitation centers
- Nursing homes
- Easter Seal centers
- Adult day care centers
- Speech/hearing centers
- Senior citizen centers
- Civic centers
- Churches
- Community halls
- Libraries
- Schools
- YMCA and YWCA
- Shopping centers or malls (some malls offer unoccupied space to nonprofit groups)

Elderly members are often reluctant to drive during evening hours, on busy highways, or if there is bad weather. Some groups don’t meet during the winter months because of weather, while others take a break in the summer when members may be too busy. Transportation can challenge your stroke support group, no matter when you schedule your meetings. Check your community services and public bus service for vans and special transportation for members who are unable to drive. Carpooling may be another solution.

Acquiring Funds for Activities and Other Expenses

Funding for stroke groups can vary greatly depending on whether a local organization has agreed to sponsor the group and its activities. Consider working with an organization or collaborating with your local American Heart Association for meeting space, use of equipment, refreshments, postage...in exchange for the members' commitment of their time to volunteer when help is needed for local stroke outreach events.

Support groups report these main expenses:

- Publicity-related: printing, copying, postage, advertisements
- Group bulletin or newsletter
- Refreshments

The group should make the decision to collect or not collect fees. Some groups collect \$1.00 annually, quarterly or monthly. Stroke groups report that the money is used mostly for refreshments. If you charge any fees, remember that some members may not be able to pay. You may consider fund-raising projects once your group is strong enough. These projects can finance events that build bonds among members.

Regarding Stroke Groups

Here are friends — people who do not shy away from us because they are uncomfortable trying to communicate with us. They have experienced, in varying degrees, the same anxieties, frustrations, anger, hopes and despair we have. Here are people who can truly share our feelings when we are “down” as well as the elation of victory when progress, however small, is made. We see others who are even less fortunate than we are and it makes us thankful. We see the accomplishments of those who have worked hard and long to make it to where they are, and it inspires patience. We see the cheerfulness and courage of those whose lives have been devastated in a manner similar to ours, and it gives us hope.

(An excerpt from “Odyssey” by Inez Thoren, caregiver, Stroke Connection Magazine November/December 1983)

How Do We Make Our Stroke Group a Success?

Developing Opportunities for Providing Caring Support

Sharing concerns and supporting each other are at the heart of any successful support group. Common experiences and challenges will draw stroke families together. But it doesn't just happen. It's a process that needs to be facilitated or "helped along." The group leaders and facilitators can set an example by instructing members in what is needed to develop a wealth of sharing and support. Three necessary elements are discussed in this section.

- Making careful word choices
- Establishing group guidelines
- Using good listening skills

Making Careful Word Choices

How stroke survivors speak of themselves and how others refer to them can affect how survivors think of themselves. The terms "stroke survivor" and "stroke victim" are an example. "Stroke victim" implies weakness and illness, while "stroke survivor" focuses on a person's resilience and hopefulness. Surviving a stroke and working at rehabilitation require strength of both body and spirit. Using the term "stroke survivor" recognizes that.

Many other words are commonly used by healthcare professionals and also stroke families, but they may be perceived as negative and demoralizing. The list of words below can help group members discuss their own perceptions and work at expressing themselves in a supportive and empowering manner.

A Language of Stroke Word Choice Exercise

YES WORDS

- stroke survivor
- experienced a stroke
- brain injury
- stroke deficits
- challenges
- a person with a disability
- caregiver/care partner

NO WORDS

- stroke victim or stroke patient
- suffered a stroke
- brain damage
- handicaps
- difficulties
- crippled
- caretaker

Establishing Group Guidelines

Setting up a number of guidelines for your stroke support group can establish the pattern for encouraging, helpful interactions at meetings. Objections to support groups raised by healthcare professionals or reluctant stroke survivors can be addressed by establishing group guidelines. Guidelines can reassure potential members who may be wary of being pushed to share more, or who fear information won't be held in confidence. Guidelines can also give the leader or facilitator a way to gently remind members of appropriate ways to interact with each other. Here are some potential group guidelines:

- Recognize and respect that every stroke survivor is unique in their injury, experience, way of coping and goals.
- A successful stroke group is a group effort.
- Information shared in meetings must be kept confidential.
- All members must be encouraged to share, or to listen, when they like, and to try to actively listen when others are talking.
- All members are expected to be non-judgmental in their responses and to be respectful of other members.
- Attempts to "fix" the problems of other members are inappropriate, but "listening is helping."
- Good listening skills help and encourage everyone.



Bright Ideas From Successful Groups

- Hold training sessions for the stroke support group leaders.
- Stay current on stroke-related issues.
- Build and maintain a volunteer pool large enough to ensure that one person doesn't have to bear all the responsibility.
- The stroke group meeting does not take the place of medical care, and we don't give medical information to each other.

Sharpening Your Listening Skills

The value of support and sharing in a group rests in members offering true, non-judgmental empathy and understanding. The great variety and magnitude of losses and concerns shared in a stroke support group can be challenging to members. Some will seem overwhelming and others small compared to what individual survivors have had to deal with.

The survivor expressing sadness over her inability to wear high-heeled shoes is not comforted by friends who comment that “it’s no big deal.” However, a fellow survivor’s reply of “I was also upset when I found I could not wear dressy shoes with a nice outfit, because it changed my whole body image,” allows the survivor to share that small loss and move past it. The key is to remember that each stroke is different, and each survivor and family handles them differently.

Communicating in a Language of Support

Basic listening skills are crucial. They give group members the ability to be helpful to other stroke families without trying to fix their problems or give advice. These skills provide a “language of support” for members who want to help each other. Members must internalize the message that “listening is helping” and understand that the goal is to help others through the process of grieving their own losses.

Group members should be told that negative responses are all too common in the normal conversations we hold with friends and family. They often cause anger, sadness and disappointment over our lack of “communication.” Unfortunately, group members can do harm if they fail to use basic listening skills. Facilitators can remind participants of conversations they had after their strokes that frustrated them or raised false expectations.

Learning basic listening skills will give members reliable skills to cope with even the most challenging stroke group discussions. The goals of learning the listening skills are:

- To encourage the person to share information and feelings.
- To show your interest and caring.
- To show you understand what you’re hearing.
- To learn to be cautious before confronting individuals or giving advice.

- To stay focused on the other person’s story and feelings.
- To respect the stroke family’s feelings and values.

Practicing Listening Skills

Listening skills instruction should be done by modeling the skills, paying attention to how members communicate and encouraging them to use the basic skills. Listening skills combine listening with prompting the group member to share concerns, resolve issues and plan for the future. The goal is to listen without bias and with respect for the speaker. Confidentiality should always be maintained. An exception would be someone qualified to help share concerns about the safety of the speaker.

These basic listening skills give the leader or facilitator a way to gently remind members of appropriate ways to interact. Discuss these skills during group meetings and practice them. Make sure members can recognize when they aren’t upholding helpful qualities and standards. Using these skills will increase the group’s effectiveness and will enhance the support that members receive. Good listening skills are your best assurance that the stroke support group will provide a safe environment and a helpful service.

Providing Basic Instruction

The listening skills aren’t complex. However, many stroke survivors and family members have difficulty abandoning old ways of communicating, particularly in a stressful situation. The skills are designed to be taught gradually and reinforced repeatedly. Many stroke survivors need time to assimilate and process the information, and then to incorporate it into their interactions in the support group.

The basic listening skills information that follows will help the facilitator introduce the concepts and lead class discussion. The facilitator should read and study them before introducing them to the class.

More detailed information on listening skills is contained in the American Stroke Association Peer Visitor Program kit. It includes detailed instructions, demonstration exercises and practice exercises. The PVP kit is available by calling the American Stroke Association Stroke Family “Warmline” at 1-888-4-STROKE (1-888-478-7653).

A Personal Experience With the Stroke Support Group

“The courage I have witnessed, the depth of feeling in which I’ve shared, and relationships I’ve established have allowed me to grow both personally and professionally. I have enjoyed the experience immensely and would recommend it to anyone as a very rewarding challenge.”

(An excerpt from “Stroke Group Development” by Mary Ellen Mussman, Stroke Connection Magazine, September/October 1993)



...basic listening skills for volunteers to remember.

- 1. Concentrate on what the other person is saying...**
...not on what you want to say next.
- 2. Encourage the person to share information and feelings.**
Ask questions that say “I care.”
- 3. Show support and caring.**
“You’re doing the best you can.”
“It’s not easy, I know.”
- 4. Show you understand what you heard.**
Respond with, “What I’m hearing you say is...”
“Did you mean that you want to...?”
“You seem concerned about...”
- 5. Use non-judgmental responses, not put-downs.**
“Every stroke is different.”
“I see what you mean.”
“Families handle things in different ways.”
- 6. Listening is helping. Listening is ENUF*!**
E Empathetic
N Non-judgmental
U Understanding
F Focused on feelings



- *Do not give advice.*
- *Do not correct, confront or judge others.*
- *Do not deny or devalue the feelings of others.*

- *Avoid comparing stroke stories.*
- *Only talk about yourself to show empathy with others.*

- *Ask caring questions.*
- *Support by listening.*
- *Provide encouragement.*
- *Offer options, helpful tips and resource information.*

*This information was adapted from: Rogers, Carl. *Client Centered Therapy*, Riverside Press, 1960; and others.

What Type of Program Activities Should We Plan?

Staying Flexible

Self-help organizations report that people are drawn to groups that provide emotional support and a sense of community. Resist the temptation to plan a full agenda of programs too far ahead or book professionals as speakers too often. This can make it hard for the group or the leaders to respond to members' needs. It's important to be flexible and to try for a balance in the type of programs offered. Time for sharing concerns, addressing problems and celebrating accomplishments is essential to developing a sense of caring and togetherness.

Striving for Balance

Educational goals and timely information are important. A good speaker and/or educational videotape can do the job. If you follow an educational program by a few carefully chosen questions, it can turn into a lively discussion and meet dual goals. Remember, schedule social time for getting to know each other and sharing.

Occasionally the group just needs a change of pace and a break from focusing on stroke. A family potluck meal, entertainment or a group outing can also stimulate new topics and new ways of helping each other. Stroke survivors can be encouraged to try things with the group that they might not try on their own, such as warm-water exercise or bowling. Stroke support groups can play a vital role in survivors' lives by providing new challenges and opportunities. Group members gain confidence after the initial period of adjustment. They may wish to extend a helping hand to others by educating their community or getting involved in stroke advocacy issues.

Involving Members in Planning

Support group leaders are often encouraged to involve group members in program planning, but this may not be easy to do. At first it may be difficult to solicit ideas as a group. Group leaders may feel pressure to "produce" large attendance numbers at the early meetings and may still be seeking that "core of regulars" to stabilize the group. It's important to assess the group membership, needs and "moods" often to find information for tailoring meetings to their needs. But at first it may be easier to poll members individually. Ask them at a time when they can answer honestly and thoughtfully. Be sure you hear from everyone, not just the most

vocal members. Make an effort to communicate with survivors who have aphasia and people who don't return after a meeting or two. As the stroke group grows and matures, this process should become easier and possibly more of a group activity. Some questions to consider:

- What did you like about the last meeting?
- What was the most helpful?
- What would you change?
- Do you feel welcomed at our meetings?
- Do you feel comfortable at our meetings?
- Are you feeling supported by the group?
- Is there enough time for visiting and sharing?
- Do you feel we are meeting our goals?
- How can we improve the service we are trying to provide?

Keeping Your Goals in Mind

Planning programs and involving members in the process may seem challenging at first. However, once the group becomes established, the ideas may be many and the time too short. The group's purpose and goals should provide a starting point and offer focus for planning programs. It's often easy to lose sight of purpose and goals when the group meets only once or twice a month and the program suggestions begin to flow. The purpose and goals should be reviewed often and updated as needed, as the membership and their needs change. When the common needs and goals are clear, it becomes easier to design interesting and successful programs.

Regarding the True Purpose of Support Groups

The personality of our group promotes warmth, sharing and well-being. Though the group provides opportunities to share hardships and concerns, the focus is more often celebrating successes and supporting strengths.

(An excerpt from "Stroke Group Development" by Mary Ellen Mussman, Stroke Connection Magazine, September/October 1993)

Providing Structure for Meetings

Support groups vary greatly in how they format their meetings, but most leaders find having a certain amount of structure to each meeting helps create an atmosphere of comfort and acceptance. Having a

regular format with certain predictable elements each time is reassuring to group members. A reliable structure can be a reminder of the group goals and ensure that time is set aside for what's important. A structured meeting format also makes it possible to create distinct roles so members can be more actively involved.

Formats can vary from a formal, business-like meeting with officers reporting old and new business, to those that simply begin with introductions and end with "See you next month!" The danger of too much "business" is a lack of time for sharing and support, and a loss of focus on the goals of the group. Too little structure can result in no sense of purpose or group cohesiveness. Again the goal of the leaders is to balance the needs and desires of the group members.

Here are some ideas to consider. Allow these suggestions to stimulate your own ideas, and you'll have no trouble developing a format for your meetings.

Group Business Items

- Welcome and introduce members and guests
- Announcements
- Read group purpose and goals
- Review group guidelines
- Highlight minutes from last meeting
- Financial report
- Social activities report
- Program planning time
- Community service planning
- Topic for following month's program
- Old or new business

Social Elements

- Share "milestones" such as birthdays and anniversaries
- Informal visiting time with refreshments
- "Icebreaker" exercise
- Share accomplishments — large and small
- Exchange of helpful resources and information
- Share inspirational quotes or readings

Meeting Program

- Facilitator or guest speaker presentation
- Planned discussion topic — large or small groups
- Videotape presentation
- Interactive group exercise
- Entertainment or social activity
- Group community outing



Bright Ideas From Successful Groups

- Gear your meetings to the needs of the membership.
 - Avoid becoming too formal in structure.
 - Don't elect officers until after the first year, if you choose to have officers.
 - Provide refreshments at meetings.
 - Be well prepared and well organized before the group starts.
 - Provide time for members to mingle, talk and get to know one another.

Beginnings and endings of any group get-together can have a tremendous impact on the mood of the group. A warm welcome sets a tone of acceptance and helps members feel comfortable. An encouraging and upbeat send-off will leave members with a good impression and encourage people to return. Some group leaders like to open with an exercise that helps members get to know each other (an "icebreaker"). A review of group goals and guidelines can also serve to "warm up" the group and remind them why they are there. Efforts to end on a positive note can be facilitated by sharing accomplishments or perhaps an inspirational quote or reading.

Regarding the True Purpose of Support Groups

The Peoria, Illinois, support group asks the following five questions at every meeting:

1. Who has a birthday this month? (Celebrants stand and share the date, but they don't have to reveal their age!)
2. Who has a wedding anniversary this month? (Couples stand and share wedding date and how long they have been married.)

3. Who has made some improvement in their physical condition this month? (Members stand to demonstrate their improvement.)
4. Who has done something for the first time that your spouse or caregiver once had to do for you? (This is an important milestone for the stroke survivor and caregiver.)
5. Has something funny happened since your stroke? (Humor is important for everyone, but particularly for stroke survivors. The group leader has a story ready, if no one has a response.)

Deciding on Educational Programs

In the changing world of healthcare, people spend less time in the hospital, in rehabilitation, and with their doctors. This makes education about stroke recovery and rehabilitation — and strategies for self-care and self-advocacy — increasingly important.

Educational programs are generally well attended because they give members practical information. They also tend to be non-threatening to people who are still uncertain if a support group is right for them. Having outside speakers may bring in large numbers, but the group can lose the intimate atmosphere needed to foster sharing and support. Remember to balance educational presentations with time for discussions and sharing. Here are some suggested topics:

Health-Related Topics

- Stroke rehabilitation presented by a variety of medical practitioners: doctor; RN; speech pathologist; physical, occupational and recreational therapist; psychologist; social worker; or dietitian
- Continuing to improve skills after rehab ends
- Impact of stroke (profiles in courage) presented by stroke survivors and their caregivers
- Stroke educational videos
- Adaptive equipment
- Stroke causes and up-to-date medical, surgical and rehabilitative care
- Physical management of stroke survivors at home and therapeutic services
- Medical questions and answers on the prevention of a recurrent stroke

- Pharmacist on medications, side effects, interactions, record keeping
- Controlling high blood pressure
- Home exercise programs
- Warm-water exercise
- How right and left hemisphere strokes cause differences in behavior
- How to help someone with aphasia communicate
- Cerebral physiology, with discussion of paralysis and paresis, seizures and anti-seizure medications
- Low-sodium, low-cholesterol and diabetic diets and healthy holiday party foods
- Drug and non-drug therapies
- Sexual functioning and intimacy after stroke

Psychological Issues

- Emotional responses to stroke and changed self-image
- Death and dying (Compare responses of families with terminally ill patients with stroke survivors.)
- Coping with stress
- Recognizing and treating depression
- Dealing with anger
- Spirituality
- Coping with stroke issues — survivor and caregiver perspectives
- Relaxation techniques
- Meditation lecture
- Psychological factors of chronic disabilities
- Communication and interpersonal family relationships

Legal and Financial Issues

- Financial impact of stroke presented by a financial advisor, lawyer or Social Security representative
- Legal rights of people with disabilities
- Employment issues
- Volunteer opportunities
- Health insurance and Medicare

- Information on Living Wills
- Social Security
- Estate planning

General

- Presentations by representatives of a local health department, civic groups, police, fire or sheriff departments, and other community resource groups
- Safety for seniors
- Travel and nature films
- Book reviews
- CPR and/or Medic Alert programs

Finding Guest Speakers

Locating speakers sensitive to the needs of stroke survivors and their caregivers is easier today, because more national attention is focused on people with disabilities. When selecting guest speakers, be sure they can interact effectively with stroke survivors. Prepare them with information on the group's disabilities and concerns. Consider tapping into the American Heart Association's and the American Stroke Association's online resources. Planning is the key to having interesting programs. Many groups plan their educational programs six months to a year in advance. Have a few contingency programs ready in case your speaker can't come. Your local library is a good resource for program content.

Meeting Special Needs

Each group member should be asked if they have any special learning challenges or needs. Larger print handouts and audio recordings of the reading materials are two ways to help stroke survivors with these special needs. If audio recordings are not possible, a survivor with aphasia might ask their spouse or a friend to read the materials to them.

Flip charts, slides and overhead transparencies help teach stroke survivors. Many need to "hear and see" what the presenter is saying to understand the material. Some stroke survivors may have trouble following a film or video and would benefit from seeing it more than once. Arrange for them to view the video at home as often as needed.

In addition, all of the speakers could be audiotaped or videotaped. This gives members who could not

attend a meeting a way to review the material. Encourage members to audiotape the presentation if they'd like to refresh their memories later.

The American Stroke Association is a good source of educational materials. Written materials include Let's Talk About Stroke, a set of 19 information sheets on topics of interest to stroke survivors and their families. Booklets on aphasia, behavior after stroke and sex after stroke are available along with many others. A series of four educational stroke videotapes on support and rehabilitation is available. Call the American Stroke Association Stroke Family "Warmline" at 1-888-4-STROKE (1-888-478-7653) for more information.

Planning Social Activities and Entertainment

These events can meet members' need for fun and outside activity. Sometimes the group just needs to take a "breather" from focusing on stroke. Here are some ideas for group activities to help you develop your own list. Outside events like these foster a more active and involved support group.

Just-for-Fun Group Activities

- Music performed by a community group
- Group birthday party
- Family potluck meal — each bring a healthy dish to share
- Restaurant meal
- Organized group games
- Field trips to museums, sports events, shows
- Picnics
- Holiday theme parties or outings
- Card playing
- Singing
- Visit other stroke support groups

Challenging Stroke Survivors

Stroke survivors may have many physical and emotional difficulties to overcome. These can give you opportunities to challenge the members of your group. Challenging stroke survivors in the group setting can help them regain confidence and become bolder about trying new activities on their own. Often an old hobby or interest can be revived with a little adaptation or a lot of practice. Plan some programs to enhance members' leisure time or help them find ways to stay physically active. Many times

no one asks a stroke survivor to do anything, because they assume the survivor can't. But no one gets better unless they are challenged. That is what recovery is about. Use the ideas below to stimulate the imagination and try something new.

- Golf
- Bowling
- Warm-water exercise
- Fishing
- Camping
- Journal writing
- Art therapy
- Music appreciation
- Arts and crafts with adaptive techniques
- Dance classes
- Horticultural and gardening tips for stroke survivors
- Photography

Encouraging Group Discussion and Peer Support

Opportunities to share concerns and to support each other are an integral part of any successful support group. For a stroke support group to truly be supportive, these elements are needed:

- Time for sharing
- Trust
- Good listening skills

Time for sharing must be set aside as a group priority. Allow enough time for everyone who wishes to participate. Recognize that smaller groups of 6–12 people are generally more conducive to sharing. Consider providing space for a larger group to break into several smaller ones. If family members attend, it helps if you encourage separate and private discussions whenever possible.

People offering personal information and insights need to be reassured that their opinions will be respected and what they say will be kept confidential. Some people are uncomfortable talking about anything personal, and their reluctance must be respected. Section III discusses setting group guidelines to help members and leaders establish a safe, comfortable process for group sharing.

Once members feel comfortable and trust the group, both the range and magnitude of losses and

concerns they share will increase. So will the challenge to group members who truly want to help but don't know how. The basic listening skills shared in Section III can help leaders, facilitators and group members provide what is needed to develop a wealth of sharing and support.

The list of "Psychological Issues" topics found under Educational Programs on page 18 can be a starting point for finding appropriate ideas for discussion topics. To facilitate helpful sharing, the focus should be on group members' feelings.

Extending a Helping Hand

Stroke survivors generally lose their community connection through loss of jobs, social affiliations and former responsibilities. With these connections gone, they easily lose a sense of their value to the community. The stroke support group can strengthen members' self-esteem by helping stroke families view themselves as educators and advocates who extend a helping hand to the local community. Stroke survivors and caregivers can have a great impact on local efforts to spread the word about stroke.

Consider these activities for more stroke group community involvement:

- Find out if there is a Train To End Stroke team in your community.
- Volunteer at your nearest American Heart Association/American Stroke Association to work at the registration table for a Heart Walk or local gala.
- Volunteer to work at a display with educational materials about heart disease and stroke.
- Set up an informative meeting on stroke for the general public or the staff of a local hospital.
- Offer to serve as "practice patients" for students of speech, occupational or physical therapy.
- Assist with mailings or other American Heart Association/American Stroke Association office duties.
- Assist at school events. Children aren't afraid to ask stroke survivors about their condition. Survivors can deliver great messages to children about health, smoking and nutrition habits.

- Ask your leaders to visit with the executive director of the local American Heart Association/American Stroke Association and offer to serve on the board or committees.
- Distribute American Stroke Association brochures and materials at health fairs.
- Get involved in service projects for hospitals, nursing homes, orphanages, and charitable or service organizations.
- Organize a stroke risk screening. This is a general assessment of someone's risk of stroke determined by a blood pressure screening and assessment. The American Stroke Association has a kit to help you plan and conduct stroke risk screenings.
- Maintain a speaker's bureau so members can speak at local civic groups and spread the word about stroke prevention. Program managers will love it.

Contact your nearest American Heart Association/American Stroke Association for a list of stroke-related materials and products or call **1-888-4-STROKE**.



Bright Ideas From Successful Groups

Regarding attendance and membership, group leaders give the following advice:

- Increase the quantity and quality of publicity regarding your support group.
- Break into small groups if your group is too large.
- Provide transportation and parking for group members.
- Avoid long programs (more than 1½ hours).
- Establish better relations with physicians and encourage their input.
- Ask support group members to visit stroke survivors who are hospitalized. Add their names immediately to your mailing list and follow up the visit with a note or card.
- Encourage stroke survivors to visit your stroke support group before they are discharged from the hospital.
- Appoint host couples for each meeting to make new members and guests feel welcome.
- Keep an up-to-date prospect list for membership.
- Make personal contact with stroke survivors' family members.

Will Our Stroke Group Continue To Grow?

A WEALTH OF IDEAS TO SHARE

Variety Is the Spice of Life

Haig Selian, a caregiver in Naples, Florida, started the Busy Stokers Stroke Group after his wife's stroke. Over the years he has developed a simple strategy for maintaining interest in the group: Do something different!

If you like your meetings sedentary or sedate, don't call Haig – the Busy Stokers do something new every week.

There is so much variety, especially since they meet every week, that everybody can participate in something sooner or later. They have done everything from bowling to putting, dog tracks to deep-sea fishing and cruising. Don't try that in Kansas!

It's helpful to remember that you don't have to satisfy everybody all the time. The larger the variety, the more people will ultimately be attracted.

A Night on the Town

Stroke group leader Marie Tolly in Louisville, Kentucky, combines a little culture with a lot of camaraderie with a group activity she sponsors through the Care and Share Stroke Group. Every month she and her group sponsor an evening of dinner theatre.

Everybody goes to the same show, so they get a group discount. The theatre, of course, benefits, but its staff also have learned how to deal better with disabled people. Although stroke group members always attend the same dinner theatre, each event is independently organized, so the responsibility for putting the evening together gets passed around.

This is a great thing for stroke survivors, because it gets them out of the house and away from the TV and puts them into a public arena. This is invaluable for their recovery.

Putting Them to Use

Stroke survivor Jim Faust in Alabama has found a good use for politicians – invite them to stroke group meetings! So far he has invited the mayor and several local legislators to talk to his group, but he has an ulterior motive: education. There may be no quicker way to educate a politician or public servant to the needs of survivors than by attending a stroke group meeting. The discussion periods of these meetings become a two-way dialog: The officials learn stroke survivors' concerns when it comes to accommodations and Medicare, and group members learn about government priorities and processes.

These meetings give elected representatives a much clearer view of what it is like to live with a disability. Besides that, stroke survivors and their caregivers are constituents, too, and their voices need to be heard.

Watching Group Members Come and Go

Attendance is a constant concern for many stroke groups. The numbers can fluctuate for no apparent reason, and members who seemed dedicated may stop attending. There are many reasons people miss meetings, and well-established groups report attendance challenges identical to those that new stroke support groups face. Poor health, transportation problems and generally stressful family situations can contribute to low attendance rates.

Surveys of members attending regularly and those who come and go may give useful information you can use to address the problem. Most groups say regular attention must be given to recruiting new members and retaining current ones. Above all, remember that numbers don't tell the whole story. An active, vibrant group doesn't need large numbers. Here are common challenges to member recruitment and attendance:

- Lack of publicity and awareness of the group.
- Lack of transportation for members who can't drive to meetings. This includes reluctance of some stroke survivors or their spouses to drive at night or in bad weather.
- Lack of doctor's referrals for new members.
- Attracting members to meetings.
- Determining membership makeup of the group.
- Too many members (very rare).
- Overcoming initial negative reaction by stroke survivors and their families to joining a group of people with physical disabilities.

Reaching Out to New Members

To ensure your group's future, recruit, Recruit, RECRUIT! Do it constantly. Show sincere interest in potential members by calling them and sending them meeting notices and support group news. Perhaps the most common (and most effective) recruitment method is having a group member who's had a stroke tell another person about the group. Enlist group members to scout out prospects and bring them to your meetings. Stroke survivors often make prospective members feel less self-conscious. This kind of sensitivity can help your group thrive.

Personal contact generates the greatest interest, so most groups simply produce a flier, descriptive pamphlet and a newsletter. Consider occasional visits with the communications director at your nearest American Heart Association/American Stroke Association office. You may find opportunities there to promote your stroke group's activities. You may be able to provide the American Heart Association/American Stroke Association office with media opportunities and ideas to help integrate stroke into their programs, events and activities.

There are many ways to publicize your group. Newspaper and magazine articles have been successful in gaining the public's interest and stimulating potential members to attend a group meeting. Other media, such as TV and radio, can give your group added exposure. Consider these ways to recruit new members:

Personal Contact

- Word-of-mouth is one of the most effective ways to spread information.

Newspaper

- An announcement sent to a newspaper can be very short, although a larger amount of information can be printed in the paper if space allows.
- The smaller community or neighborhood newspapers may be willing to print more information than larger ones.
- If your group has one or more sponsors, they may be able to help you generate this form of publicity. For example, a staff person at a sponsoring agency will probably have a list of media contacts. (That's another good reason for you to work with a sponsor as you organize your group.)

TV and Radio

- Local TV channels or radio stations usually produce community-interest programs where your stroke group meetings can be announced each month.

Other Media

- Invitations given to stroke patients by healthcare professionals
- Letters
- Telephone calls
- Posters
- Bumper stickers
- Seminars
- Referrals from the local American Heart Association or Easter Seal Society
- Community program announcements

Keeping Members Informed and Involved

If you want loyal group members, find relevant jobs for them to do. When members are involved in running the group, it becomes more "their group" and they will take on more responsibility. Some groups have officers, committees and sponsoring agencies. Some rely on professional staff to organize their programs. Others are directed by a committee. Clearly spell out the areas of responsibilities for your group, decide how people will be selected and how long they will serve. Committees can carry out many duties like telephoning potential members, sending cards and letters to members, keeping a group scrapbook, membership records, producing a newsletter, program planning, publicity, refreshments, social activities and visitation.

Every aspect of a stroke support group presents opportunities for recovery. Survivors can gain self-esteem with each step while doing something that lets them see the fruit of their labor.

If you're having difficulty with attendance or meetings, consider these ideas:

- Promote interaction among members between meetings.
- Start a telephone committee to call members and remind them of upcoming meetings.
- Organize a transportation committee to bring members to the meetings.
- Produce a newsletter.
- Involve members on a program committee to plan programs, activities and other events.
- Identify candidates for leadership roles.

Here's the bottom line on improving attendance and retaining membership in your support group:

- Make the group indispensable in the lives of your members by challenging them in ways that society as a whole will not. You never know what people can do until they're asked. Experience shows that the stroke survivors who transform their lives are the ones who are progressively challenged to do more than they're doing.

Consider these methods of communicating with members:

Pamphlets and Newsletters

- Consider a newsletter or a one-page fact sheet about your group.
- Newsletters are a popular form of publicity because they're more personal than newspapers, TV or radio. See Section VI of this guide for resources on publishing a group newsletter.

Bulletins

- A bulletin could list the name of your stroke group, where your meetings are held, the time and date of your meeting (for example, the fourth Tuesday of the month), and a contact person and phone number.



Bright Ideas From Successful Groups

- Create a buddy system to foster caring communication among members and help new members feel at home.
- Acknowledge all members for the contributions they make.
- Increase family involvement.

Finding the Secret Formula for Success

If there's a secret formula for stroke group success, it's flexibility. Determine what the members want, survivors and caregivers alike. Take into account the levels of disability, then give your members what they need to get what they want. Like in a one-room school, the more experienced members help the new arrivals.

A survey of stroke support group leaders discovered these ingredients in their formulas for success:

- Members' interest and enthusiasm, the single most important factor
- Members' positive attitudes about their support group
- Friendships among members
- Maintenance of strong core groups
- Members that care for one another
- Motivation and persistence
- Focusing on successes rather than failures
- Recognition of members' accomplishments
- Sharing experiences
- Making members feel needed
- An inspirational group leader
- Spouses' support of the group

You may not find your own workable combination of ingredients overnight, but the process should be half the fun!

Regarding That Special Day of the Month

“On one day of the month we look forward to seeing and being with these gallant people. Oh yes, the wide variety of programs makes it interesting, informative, inspiring and entertaining. But it is the people who draw us to this group — we see the warmth of their smiles when we greet them, to feel the squeeze of a hand and know the empathy and love which prompt it, to share a small moment of triumph in our own or someone else's odyssey — this is what makes stroke group the supportive and helpful occasion that makes that day special on our calendar each month. Blessings on stroke groups!”

(An excerpt from “Odyssey” by Inez Thoren, caregiver, *Stroke Connection Magazine* November/December 1983)

What Resources Are Available To Help Group Leaders?

Note:

This information is provided by the American Stroke Association as a resource list for our readers. The organizations, associations and foundations listed are not owned or provided by the American Heart Association, with the exception of the American Stroke Association, a division of the American Heart Association, and American Stroke Association itself. Additionally, the organizations may not have been evaluated, so this list should not be construed as a recommendation or endorsement by the American Stroke Association.

National Resources

We at American Stroke Association are dedicated to giving you a helping hand. The Stroke Family Support Network serves as a resource for the most up-to-date stroke information. We also want to share information about some of the many organizations that have resources available for stroke support group leaders. Many are a toll-free phone call away. We urge you to keep this list and use these organizations as often as necessary. And, of course, if you want that one-on-one attention from someone who has been in your shoes, call the **American Stroke Association Stroke Family “Warmline” 1-888-4-STROKE (1-888-478-7653)**.

American Stroke Association, (a division of the American Heart Association) Stroke Family “Warmline”

7272 Greenville Avenue
Dallas, Texas 75231
1-888-4-STROKE (1-888-478-7653)
www.StrokeAssociation.org

A toll-free referral and information line, free stroke materials, daily living tips, referrals to stroke support groups, a national stroke support group registry, and the award-winning *Stroke Connection Magazine*. The Stroke Family “Warmline” also offers a variety of educational support services for stroke survivors, caregivers, family members and healthcare professionals.

General

American Association of Retired Persons (AARP)

601 E Street, NW
Washington, DC 20049
800-424-2277
www.aarp.com

AARP provides information relating to aging and senior citizens. It also has literature for a variety of health and benefit questions important to seniors.

U.S. Department of Health and Human Services

Public Health Service – Agency for Health Care Policy and Research

P.O. Box 8547
Silver Spring, MD 20907-8547
800-358-9295
www.ahrq.gov

Governmental publications are available on a variety of stroke-related topics, including the widely acclaimed Post-Stroke Rehabilitation Clinical Practice Guidelines and Recovering After a Stroke: Post-Stroke Rehabilitation Patient and Family Guide.

Rehabilitation

American Academy of Physical Medicine and Rehabilitation

1 IBM Plaza, Suite 2500
Chicago, IL 60611
312-464-9700
www.aapmr.org

This is an automated information line that provides listings of physiatrists in local areas.

American Occupational Therapy Association

4720 Montgomery Lane
Bethesda, MD 20814
301-652-2682
www.aota.org

This association helps people locate occupational therapists in their local areas.

American Physical Therapy Association

1111 North Fairfax Street
Alexandria, VA 22314
800-999-2782 or 703-684-2782 or
www.apta.org

This national organization provides referrals to state chapters.

American Speech-Language-Hearing Association

10801 Rockville Pike
Rockville, MD 20852
800-638-8255 or 301-498-2071
www.asha.org

This organization can provide a list of speech therapists in your state.

National Aphasia Association

29 John Street, Suite 1103
New York, NY 10038
800-922-4622
www.aphasia.org
e-mail: naa@aphasia.org

This organization provides information and support services for people living with aphasia.

National Association of Social Workers

750 1st Street NE, Suite 700
Washington, DC 20002
800-638-8799 or 202-408-8600
www.naswdc.org

This national association provides a list of local social workers.

National Easter Seal Society

230 West Monroe Street, Suite 1800
Chicago, IL 60606
800-221-6827
www.easterseals.org

This organization helps people with disabilities achieve independence by locating funding sources to assist with medical and assistive equipment and medical bills (on occasion).

National Institute of Neurological Disorders and Stroke

P.O. Box 5801
Bethesda, MD 20824
800-352-9424
www.ninds.nih.gov

This organization receives funding from the National Institutes of Health and provides clinical information packets on stroke.

National Rehabilitation Information Center

4200 Forbes Blvd., Suite 202
Lanham, MD 20706
800-346-2742
www.naric.com

This toll-free number provides information on types of rehabilitation, adaptive devices and other aids for recovery.

Vocational Services for the Disabled

800-222-JOBS

A New York-based service that refers consumers to local state offices providing vocational and educational services for people with disabilities.

Caregiver**Eldercare Locator**

927 15th Street, NW, 6th Floor
Washington, DC 20005
800-677-1116
www.eldercare.gov

A nationwide database that gives caregivers access to local area resources that provide care to the elderly.

Family Caregiver Alliance

690 Market, Suite 600
San Francisco, CA 94104
415-434-3388
(in California 800-445-8106)
www.caregiver.org

This organization provides caregiver support and educational opportunities through research, advocacy, legal consultation and training workshops.

Flying Wheels Travel

143 West Bridge St.
P.O. Box 382
Owatonna, MN 55060
507-451-1685
www.flyingwheelstravel.com

This for-profit travel agency provides worldwide travel assistance for the disabled for leisure and vacation purposes only.

National Council on Aging

409 Third Street SW, Suite 200
Washington, DC 20024
800-375-1014
www.ncog.org

This organization provides lists of community resources that help improve the quality of life for the elderly.

National Family Caregiver Association

10400 Connecticut, Ave., Suite 500
Kensington, MD 20895-3944
800-396-3650
www.nfcacares.org

Mental Health

American Association of Suicidology

4201 Connecticut Ave., Suite 408
Washington, DC 20008
202-237-2280
www.suicidology.org

This association provides information on suicide and a referral to the nearest suicide crisis center in your area.

American Psychiatric Association

1400 K Street, NW
Washington, DC 20005
202-682-6000
www.psych.org

This organization provides information on choosing a psychiatrist as well as research on emotional illness.

National Foundation for Depressive Illness

P.O. Box 2257
New York, NY 10116
800-239-1265
www.depression.org

This foundation provides information and referrals to the public about depressive illnesses.

National Institute of Mental Health

6001 Executive Blvd., Room 8184
Bethesda, MD 20892-9663
800-421-4211
866-615-6464
www.nimh.nih.gov
e-mail: nimninfo@nih.gov

This organization is an educational resource for the general public as well as healthcare professionals on the co-occurrence of stroke and depression.

Financial

Medicare Hotline

800-MEDICARE
800-638-6833
www.medicare.gov

Call this toll-free number for information about Medicare and financial assistance for persons over 65. They can also help find medical specialists in local areas.

National Insurance Consumer Helpline

110 William Street
New York, NY 10038
800-942-4242

This toll-free number gives assistance with questions about health and life insurance as well as information about individual health insurance companies.

Social Security

800-772-1213
www.ssa.gov

A national toll-free number that provides assistance with Social Security benefit questions and makes referrals to local Social Security offices.

Employment

ADA Helpline — Equal Employment Opportunity Commission

P.O. Box 12549
Cincinnati, OH 45212-0549
800-669-4000

This is a toll-free number for information about discrimination against people with disabilities in the workforce.

Higher Education and Training for People With Handicaps

800-544-3284

This is an automated information line that provides information on post-secondary education for the disabled.

IBM's National Support Center for Persons With Disabilities

800-426-4832

This is a clearinghouse to help healthcare leaders, agency directors, policy makers, employers, educators, public officials and individuals learn how computers can enhance the quality of life in the school, home and workplace for persons with disabilities.

Patient Rights

People's Medical Society

462 Walnut Street
Allentown, PA 18102
610-770-1670

This organization provides information to make every American a smart healthcare consumer.

Children

National Information Center for Children and Youth with Disabilities

P.O. Box 1492
Washington, DC 20013
800-695-0285
www.nichcy.org

This is an information, resource and policy center focusing on adolescents with chronic illnesses and disabilities and the issues surrounding their transition to adult life.