

Starting a STROKE SUPPORT GROUP

Why start a Stroke Support group?

People who have suffered a stroke often have special needs due to the particular disabilities they develop as a consequence of the stroke. But most importantly are the general needs that we all have for social interactions. For someone who has suffered from a stroke, there are many barriers to social enjoyment.

Access to social situations may be difficult for a number of reasons. The person may avoid social situations because of their speech, cognitive or physical difficulties, and they may feel embarrassed by their disabilities. Loss of confidence may lead to social isolation and loneliness. Furthermore there may be no opportunities in the community for social interaction. Individual members may also have issues with transportation and getting around the local community. These are all good reasons to consider developing a Stroke Support group in your local area.

Other reasons may be the need to work together on rehabilitation techniques such as movement and speech outside a hospital setting, and to enjoy outings together. Individuals also find it valuable to socialise with those in a similar situation, and to transfer personal knowledge of their condition.

Planning for a Stroke group

Find out how much support there is in your area for a Stroke group, and how many people are likely to join it. There may be a group in the surrounding area or a group in your area you can link in with. To do this, contact your local Community Health Centre, Citizen's Advice Bureau, Community Rehabilitation Centre, Local HACC providers and other related organisations.

It is helpful if these organisations can be involved, as they will be an ongoing source of referrals for new members and may also be able to participate in the planning and organisation of the group. They may also be able to assist with facilitating the group.

Where should meetings be held?

Preferably where you can have the use of the premises rent-free. Approach your local council to find out what's available in your area. The ideal venue for a support group meeting is a room large enough to allow your members to move around easily and which is well heated in winter. It should be close to public transport for those members who use this method of transport.

It is important that there are suitable toilets for those members in wheelchairs. Facilities should be available for making tea and coffee. The room should be accessible for wheelchairs, and street access should be easy. The room should have tables and chairs that are accessible.

When should the meetings be held?

This may be dictated by the availability of the premises. If there is a choice, the main factor to be taken into consideration is the type of group you have in mind. If possible have an interest meeting and let the interested persons have some choice in the day and time. Included in this meeting should be local service providers and the general public.

How often should meetings be held?

Again this may be dictated by the availability of premises and facilitating staff. It may also be influenced by the number of helpers available. Many Stroke groups meet fortnightly, others monthly. Local needs and resources will determine your decision, but the more frequent the meetings the better. Generally, meetings are held for the duration of 2-3 hours.

How should we publicise the group?

Once the working party has finalised all the arrangements to launch the group, it is useful to hold a public meeting to publicise the group and encourage people to join as members or helpers. Notice of the public meeting should be circulated to all voluntary organisations and statutory agencies such as Health & community services, community health services, local library, citizens' advice bureaux. To ensure that prospective members know of the meeting, notify hospitals, day centres and GPs. Ask the local press if they will publish a paragraph about the proposed group - a picture of the group leaders is a good idea.

Ongoing publicity can be sustained through the local press and a poster campaign. It may be useful to make up posters on which you could insert details of your group or publicise a particular function. Having pamphlets available for GP offices and local hospitals is also of value in recruiting new members, even if it's just black & white printing on an A4 sheet of paper.

What Therapeutic activities will we need to organise?

The scope of activities which a lively and well-run group can undertake, is almost limitless.

Stroke group activities should always be positive and aimed at furthering self-management and increasing members' confidence. Some activities should be geared to helping members cope with the tasks of everyday life so that they can take their place in the community again. Many people who have incurred a stroke suffer from depression and apathy, and they need help and encouragement if they are to find new interests in life and take up new hobbies. For many, learning to speak in a social setting is an important need, which can be tackled in such a group.

What Social activities should we arrange?

Members who are housebound, apart from visits to the group, will appreciate having the services of a massage therapist, or visits from other local community groups and services.

Trips out to lunch can be both enjoyable and helpful. Remember that costs should be kept to a minimum as many members are reliant on pensions.

The group will probably want to arrange outings for members, and if you include relatives you will have extra help on hand. It is important to visit your destination first; or to discuss with the proprietor issues such as whether adequate parking is available or that access to main areas and toilets are suitable for your group's needs. It will help if you give advanced warning of your visit to those concerned.

In summer, you could organise visits to gardens, beauty spots, stately homes, outdoor shows or the beach. In winter, the group could visit a theatre or concert or go to the local cinema. Remember that many theatres offer discounts for groups and for those with a health care card. This also is the case for many entertainment venues. Other ideas are the museum or Science-Works.

Another area may be sporting activities. Besides indoor games such as ten-pin bowling, table tennis or billiards and darts, enterprising groups can arrange lawn bowls, or swimming sessions at local pools, or hydrotherapy.

What is important is that you encourage your members to choose their own activities, and have some planning days to arrange activities.

Should relatives be invited to attend the meetings?

This will largely depend on the type of group you plan. Some groups find that the presence of relatives inhibits members, and they prefer them not to attend; on the other hand some members have extra confidence when someone from their family is present.

It is important that contact is maintained between home and group, and that the families know about the group's activities, so that the member can talk to them about the meetings they go to. One possibility is for relatives to meet regularly as a separate group to discuss shared problems with professionals, or just amongst themselves, at the same venue.

Duty of Care

This is an important area to consider before getting started. It will be wise to check that insurance cover is in place and adequate for any activities you plan.

Transport of group members may require special arrangements. Where therapeutic activity is planned, care should be taken to ensure the safety of each member, and of the members staffing the group. The person and their family/carers should be consulted as to the person's capacity for any planned activity.

Funding

Funding is available to self-help groups through the Department of Human Services. Monies are granted to groups to help with the administration costs, such as letters to members and hall hire. It does not cover costs for speakers or activities. Applications for this are available in February from the Department of Human Services.

See www.dhs.vic.gov.au/disability/building_better_communities/self_help_funding, or call them on (03) 9096 7921.

Many groups have a small joining fee of about \$5 to assist in purchasing items such as tea, coffee and cake. A donation of a \$1 per person per meeting is also worth considering. Fundraising can also bring monies into the group to help pay for many activities. Again, fundraising can only be limited by your imagination.

Useful contacts:

COSHG (Collective of Self Help Groups): www.coshg.org.au or call (03) 9349 2301. They provide information on starting & running groups, & also run occasional workshops.