

More support for more people

Starting a Stroke Support Group



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About the Stroke Association

Our vision

We want a world where there are fewer strokes and all those touched by stroke get the help they need.

Our mission

Our mission is to prevent strokes, and reduce their effect through providing services, campaigning, education and research.

Stroke helpline

0303 303 3100

Website

www.stroke.org.uk

The Stroke Association is registered as a company limited by guarantee in England and Wales No. 61274. Registered charity No. 211015 and registered charity in Scotland No. SCO37789.

What is a stroke support group?

A stroke support group provides vital social support and activities for those affected by stroke. There are over 500 groups across the UK that meet regularly and provide everything from information and advice, days out and exercise, understanding and a cup of tea.

This guide gives ideas and advice on how to start a new support group and things to think about in the first few months of setting up.

Who can start a group?

Support groups are usually started by someone who has an interest in stroke and has identified a need for a new group. This could be a stroke survivor, a carer, family member, or a health or social care professional.

It is often helpful to have the support of the local NHS when starting a group. Those working with people affected by stroke will be in a good position to help promote the group and recruit new members.

In the longer term, support groups tend to run by volunteers and willing helpers who share the task of organising the group between them.

Most groups have an elected committee with a chairperson, secretary and treasurer, whilst others opt for a more informal structure (see 'Getting organised').



Types of group

Most support groups welcome people affected by stroke from across their local area and offer a variety of activities such as talks, days out, games and quizzes, and above all an opportunity to meet and chat with others.

There are also groups that offer more focused activities:

Exercise

An increasing number of groups take part in seated exercise sessions as part of their regular meetings, run by a qualified person.

Communication support

Communication difficulties (or aphasia) are a common side effect of stroke. Some groups offer specific support for those who have been affected.

People of working age

Some groups welcome members who have been affected by stroke under the age of 65.



Art groups

Art can be a useful therapy for those who've had a stroke, and some groups run drawing and painting activities for their members.

Community specific

In some areas there is a need for a group that meets the needs of its local community, for example Asian or Afro-Caribbean.

Of course, this list is not exhaustive, and any group can organise any sort of activity for its members, either as a one-off or as part of regular programme.

Independent Groups

Many groups chose to be independent of any national or regional organisation. An independent group has a constitution setting out its aims and objectives, its own bank account and its committee will work to provide activities for its members that are both enjoyable and safe.

The Stroke Association is keen to work with all groups and it's affiliation scheme is one way that is strives to do that (see 'Next steps').

Stroke Association Voluntary Groups

A Stroke Association Voluntary Group operates under the umbrella of The Stroke Association. Volunteers and committee members run the group but with support from regional and national staff. The group will sign a charter that sets out what the group aims to do, and follows guidelines set out by The Stroke Association that will ensure the group is safe and complies with charity law and other legislation. It also benefits from:

- Comprehensive insurance covering members and volunteers;
- Use of The Stroke Association's charity number for fundraising;
- Promotional materials;
- Support from regional and national staff;
- Help with volunteer recruitment, fundraising, media and campaigning;
- Training, including on health and safety, client assistance;
- Free places at the UK Stroke Club Conference.

More information on becoming a Stroke Association Voluntary Group is available from your regional office or the Stroke Club and Partnerships Manager (see 'Useful contacts').

Getting started

Having identified the need for a new group, the biggest decision is to start the group. Having made that decision, there are a number of things to consider and steps to follow.

Step One

Who is going to help you?

Setting up a new group by yourself can be hard work so it is a good idea to find some likeminded individuals who can help and support you.

Getting a group going is rewarding but it is a case of ‘the more the merrier’ when it comes to making decisions and overcoming difficulties.

Forming a small working group can be a good way of getting going and could include:



- Interested local health and/or social care professionals;
- Stroke survivors and their carers who would like there to be more long term support;
- Local Stroke Association staff member.

Even if you can't persuade a health or social care professional to help you, keep your local Stroke Unit up to date. They may be able to help at a later stage by encouraging people to join.

Step Two

Making plans

Having formed an informal group, it is a good idea to meet up and think through how you are going to approach setting up the new group. You may wish to discuss some of the following:

- What type of group you want to set up;
- Where the group is going to meet;
- Frequency of group meetings and what time of day;
- Where to find potential members and how to promote the group to them;
- Ideas on finding potential volunteers and/or committee members.

The planning stage often raises more questions than it answers. This is normal. Don't forget that your regional office and the UK Stroke Club Coordinator can help with these.

Having thought through some of the issues and answered some the main questions, it is useful to draw up a rough plan of what's going to happen, who's going to do which bit, and when.

If you have decided or are thinking about setting up a Stroke Association Voluntary Group then request a copy of the *Stroke Association Voluntary Group Handbook*.

Ideas for meeting venues

Community centres, church halls, sheltered housing, education room at GP surgeries, YMCA rooms, sports centre and clubs...

Ideas for recruiting members

Ask your Stroke Unit to send a letter to their patients, put up posters in the hospital and local community, put an advert in the local paper...

Get ideas from those with experience

Your regional office can put you in touch with other local groups who may be able to offer their advice on getting going, as well as their support.

Step Three

Holding the first meeting

Making plans is important, but the focus of the plans should be the first meeting, of which there are two types:

1. Where a group of potential members and/or volunteers are already interested and are invited to come together to find out more;
2. Where those invited are new to the idea of a group and have come along to find out what's being planning and whether they want to be involved in some way.

Whichever type of meeting you are planning (or even it's a combination of the two), it is worth doing some preparation to make sure it goes well. Here are some ideas:



- Make sure there is tea, coffee and biscuits;
- Make sure the meeting has a focus that people will enjoy and/or get something out of. This could be inviting a health professional to do a talk and question and answer session on stroke, or an activity that gets everyone involved, maybe a quiz or an exercise session;
- Have an idea about what future meetings may look like. The best thing is for people to go home already looking forward to the next one;
- Don't forget to get people's contact details so you can contact them in the future.

Getting organised

Many people are put off from getting involved with the setting up or running of a support group because it can seem like there is a lot of paperwork and organising. It is important to break down the tasks to be done as much as possible. This section outlines the main considerations in making sure the group is well run and provides a safe environment for its members.

The Committee

Once a group has decided to set up, it will need a group of people to help run it. This is commonly called a committee, although the name can be off putting to some people. To ensure that individuals aren't overloaded, it is recommended the group has a minimum of three people: chairperson, secretary and a treasurer.

Chairperson

- Attend and chair group and committee meetings;
- Ensure that the committee and group are following rules and guidelines.

Secretary

- Manage any paperwork relating to the group;
- Hold the contact details of members and volunteers;
- Keep minutes of committee meetings.



Treasurer

- Keep records of all income and expenditure;
- Manage the group's bank account;
- Be the main contact for financial issues within the group.

Many groups have more committee members that take on other roles, such as Vice Chairperson, Newsletter Editor, Fundraising Officer or Outing Coordinator.

When groups start, committees tend to be self-elected in order to get the ball rolling. At the group's first Annual General Meeting (AGM), the committee is then voted into office by the members.

Governing Documents

It is important for a group to be clear about what its aims and objectives are.

An independent group will have a constitution that lays down what the group will be doing as well as how it will run. It may not seem like the most important thing to have in the beginning but many problems that groups face over time can be avoided by having a clear constitution. Some grant-making bodies will request to see the group's constitution before deciding whether to give the group any funding. It can also be a requirement of affiliating with other organizations, such as The Stroke Association. Request a copy of the factsheet *Adopting a Constitution* from your regional office or the Stroke Club and Partnerships Manager.

A Stroke Association voluntary Group operates under the constitution and charitable status of the main organisation. The group will sign the Voluntary Group Charter, with guidance on how the group is run being set out in the *Stroke Association Voluntary Group Handbook*.

Insurance

Every support group will need to have insurance cover in place in case of accidents or injuries. It will ensure that the groups, its members, volunteers and committee members are protected against any claims made against it.

Public Liability Insurance

Also known as third party insurance, public liability insurance protects the group from claims by members of the public in the case of death, illness, loss, injury or accident caused by the negligence of the group.

Employers Liability Insurance

It is a legal requirement for any group or organisation that employs members of staff to have employers liability insurance. It covers employees in the event of accident, disease or injury caused or made worse as a result of work or employers negligence. Volunteers are often treated as employers in law and so it is recommended that groups have this level of cover.

Insurance, at a negotiated rate, is available to support groups that are affiliated to The Stroke Association (see 'Next steps').

Stroke Association Voluntary Groups are insured under The Stroke Association's insurance cover.



Health and Safety

The aim of all stroke support groups is to offer safe and enjoyable activities for its members. A Health and Safety Policy is an important part of this, for example setting out what to do in an emergency, working with vulnerable adults and first aid provision.

Independent groups are recommended to draw up and adopt a policy, and can get guidelines and a sample policy from your regional office or the Stroke Club and Partnerships Manager.

Stroke Association Voluntary Groups fall under The Stroke Association's Health and Safety Policy, which is summarised in the *Stroke Association Voluntary Group Handbook*. Full training and support is given to groups on this area.

Finance

Stroke support groups are self-funded, usually through a combination of member subscriptions, fundraising activities and grants. A record of all income and expenditure will need to be kept by the group, and groups will usually need a bank account in order to keep their funds safe, which should have a minimum of two unrelated, unmarried signatories.

New groups are often able to apply for grants from the local council or volunteer bureau to help get them started. The Stroke Association offers a £100 start up loan (or grant for Stroke Association Voluntary Groups) designed to cover the initial costs association with a new group, such as venue hire or refreshments (see 'Appendices').



Please note:

The Stroke Association has no control or access over the funds of any independent group, but is happy to advise groups on their finances if requested to.

Stroke Association Voluntary Groups will have a bank card opened for them which they will then manage themselves locally.

Next steps

Once your new stroke support group is up and running, don't forget to tell The Stroke Association. We hold a list of all groups across the UK and our helpline refers thousands of people every year to their local group. Please use the form in the 'Appendices'.

Stroke Club Affiliation Scheme

The affiliation scheme is the main way that The Stroke Association works with independent groups. A summary is given below with more information available from your regional office or the Stroke Club and Partnerships Manager.

Support for you

- Free copies of Club Together, the quarterly newsletter for Stroke
- Clubs;
- Free postage and packaging on all Stroke Association leaflets and publications;
- Regular email updates for those running clubs, including the latest news on fundraising, campaigning and the work of The Stroke Association;
- Access to specialist advice as needed, for example on health and safety or legal issues;
- Resources to help clubs ensure they are working legally and to best practice standards, including the 'Stroke Club Toolkit'.



Marketing your club

- Listing on The Stroke Association's website, www.stroke.org.uk,
- directing potential new members and volunteers to your club;
- Specialist online software enabling your club to have professional looking leaflets and posters printed at competitive prices.

Looking after members and volunteers

- Access to a tailor made insurance package designed and competitively costed especially for Stroke Clubs;
- Free Criminal Record Bureau checks for volunteers (as needed and determined by the club);
- Discounted first aid training through St John Ambulance.

Training and events

- Free training courses on a wide range of subjects for volunteers and committee members;
- An 80% discount on places at the annual UK Stroke Club Conference.

Registering as a charity

Many people believe that all charities have to be registered in order to undertake any fundraising. This is not the case. Registering as a charity is only a legal requirement for groups whose income exceeds £5,000 in a twelve month period. Groups whose income is less than £5,000 can continue to fundraise as a charitable group although it is advised that they adopt a constitution.



Independent groups (affiliated or otherwise) are not able to use The Stroke Association charity number as they are not part of the organisation.

Stroke Association Voluntary Groups operate under the umbrella of The Stroke Association and so are able to use the charity number in any fundraising they do.

Useful contacts

Stroke Association

Stroke Club & Community Partnerships Manager

Liz Roberts
0161 742 7488
liz.roberts@stroke.org.uk

East of England

Tracy Groves
01284 848 605
tracy.groves@stroke.org.uk

London

John McGlone
020 7940 1341
john.mcglone@stroke.org.uk

North East

Donna Stott
01914 978 322
donna.stott@stroke.org.uk

North West

Scott Smith
0161 742 7479
scott.smith@stroke.org.uk

West Midlands

Stuart Cooper
01527 903 711
stuart.cooper@stroke.org.uk

South Central

Ian Stiff
02380 720 422
ian.stiff@stroke.org.uk

South East Coast

Zuher Panju
01883 333 031
zuher.panju@stroke.org.uk

South West

Sarah Day
01202 694 883
sarah.day@stroke.org.uk

Wales (North)

Rebecca Chamberlain
01745 508 530
rebecca.chamberlain@stroke.org.uk

Wales (South & East)

Lucy Thomas
0292 052 4408
Lucy.thomas@stroke.org.uk

Yorkshire & East Midlands

Maria DeGiorgio
0115 871 2466
maria.degiorgio@stroke.org.uk

Those interested in setting up groups in Scotland and Northern Ireland should contact the Partnerships Manager.

Charity Commission

0845 300 0218

www.charitycommission.org.uk

Charity Facts

www.charityfacts.org

Community Service Volunteers

020 7278 6601

www.csv.org.uk

Volunteer Development Agency, Northern Ireland

028 9023 6100

www.volunteering-ni.org

Volunteer Development Scotland

01786 479 593

www.vds.org.uk

Vol Resource

www.volresource.org.uk

Volunteering England

0845 305 6979

www.volunteeringengland.org.uk

Wales Council for Voluntary Action

0870 607 1666

www.wcva.org.uk



New Group Details Form

The information given on this form will be used to update our internal database and Stroke Helpline.

Full group name _____ Date formed _____

Meeting details

Meeting place address _____

Postcode _____

Meeting day _____ Meeting frequency _____

Opening hours _____

Transport provided? _____ Annual review meeting month _____

Activities offered

- | | | |
|--|--|-----------------------------------|
| <input type="checkbox"/> Social support | <input type="checkbox"/> Outings & meals | <input type="checkbox"/> Exercise |
| <input type="checkbox"/> Speakers | <input type="checkbox"/> Games & quizzes | <input type="checkbox"/> Art |
| <input type="checkbox"/> Communication support | Other activities _____ | |

Contact details

Name of main contact _____

Address _____

Postcode _____

Phone _____ Email _____

Promoting your group

We promote your Stroke Club on our stroke helpline using the information on this form. If you do not want us to do this, please tick this box.

If there are specific pieces of information on this form that you do not wish to be included on our stroke helpline database, please give below. _____

Support Group Start Up Funding Application Form



The Stroke Association offers start up funding of £100 to support new stroke support groups. This takes the form of an interest free start up loan for independent groups, or a grant for Stroke Association Voluntary Groups. It is hoped that this will be used to help cover initial venue hire and administration expenses, until the group can begin its own fundraising activities.

Independent Groups Start Up Loan

The loan is made to Stroke Clubs that intend to become self-funding and self-led with a constitution, and has a group bank account with two unmarried, unrelated signatories. The loan should be repaid once the group has £700 in their bank account.

Stroke Association Voluntary Groups Start Up Grant

The start up grant is made to Voluntary Groups that have started within the last 12 months, and it is expected that the group remain as part of the Stroke Association for five years after the grant has been made, otherwise the grant will be repayable. The group must have signed the Voluntary Group Charter, and have a bank account.

If you meet the above criteria and would like to apply for start up funding, please indicate if you are applying for a loan or grant above, and complete the information below.

Please return the form to the Community Partnerships Finance Support Officer, Stroke Association, 6th Floor St James House's, Pendleton Way, Salford, M6 5FW.

Group name _____

Name of Main Contact _____

Address _____

Postcode _____

Telephone _____ Email _____

INTERNAL USE ONLY

Date received _____
 Request to Finance _____

Region notified _____ Region _____
 Acknowledgement from group _____