

stroke.org.uk

Stroke
association

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

stroke.org.uk

Stroke Association is a Company Limited by Guarantee, registered in England and Wales (No 61274). Registered office: Stroke Association House, 240 City Road, London EC1V 2PR. Registered as a Charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Northern Ireland (XT33805), Isle of Man (No 945) Jersey (NPO 369).

What is a stroke support group?

A stroke support group provides vital **peer support and activities** for people affected by stroke. Groups provide a huge range of information and activities such as days out, exercise, art, a cup of tea and an understanding ear. **Meeting other people affected by stroke** and chatting is one of the most important things stroke groups offer.

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

Who can start a group?

Clubs and groups are 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.

In the longer term, **groups tend to be run by volunteers** who share the task of running and organising the group.

Types of group

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

But some groups are more specific, including:

- Carers
- Creative arts
- Support
- Singing
- Telephone
- Exercise
- Gardening
- Walking
- Communication/Aphasia



There are also community specific groups that meet the needs of a specific local community, such as Afro-Caribbean communities or people of working age.

Groups can organise any sort of activity for its members, either as a one-off activity or as part of a regular programme.

Stroke Association Voluntary Groups

A Stroke Association Voluntary Group **is part of the Stroke Association**. Stroke Association volunteers run the group. The group will sign a charter that sets out what the group aims to do. It must **follow the guidelines and policies set out by the Stroke Association**. This ensures the group is safe and complies with charity law and other legislation.

It also **benefits** from:

- Comprehensive **insurance**
- Use of the Stroke Association's charity number for fundraising
- **Promotional materials**
- **Support from regional and national staff** with volunteer recruitment, fundraising, media and campaigning
- Free **training**, including supporting people with aphasia and first aid
- Heavily subsidised places at the UK Stroke Club Conference

More information on becoming a Stroke Association Voluntary Group is available from the Volunteering and Community Officer in your area, or from our Stroke Association Voluntary Group Handbook.

Independent Stroke Clubs

Some clubs choose to be independent of any national or regional organisation. They are generally referred to as clubs rather than groups. An independent club is its **own, separate organisation** with its own constitution that sets out its aims and objectives. Activities are similar to those of a voluntary group but the **committee has full legal responsibility for the group**.

The Stroke Association is keen to work with all clubs, and our affiliation scheme is one of the ways we do that (see 'Next steps').

Getting started

Having made the decision to start a club or group, 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 people who can help**. Involving more people in decision-making will help the group make better decisions.

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

- Local health and/or social care professionals;
- Stroke survivors and their carers
- Local Stroke Association staff member.

Even if the health or social care professionals aren't able to directly help, keep them up to date. They may be able to support at a later stage by encouraging people to join.



Step Two: Making plans

Having formed a working group, it is a good idea to meet up and make a plan.

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 members and how to **promote the group**
- Ideas on **finding volunteers**.

Don't forget that your local Volunteering and Community Officer can help with any questions and support you throughout the process.

Having thought about some of the issues and answered some the questions, **draw up a rough plan** of what's going to happen, who's going to do which bit, and when.

Your Volunteering and Community Officer can help with this, so get in touch with them for more information.

Ideas for meeting venues

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

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 and support.

Step Three: Holding the first meeting

There are two types of first meeting:

1. Potential members and/or volunteers are already interested and are invited to come together to find out more
2. People invited are new to the idea of a group and have come along to find out what's being planned and whether they want to be involved.

Whichever type of meeting you are planning (or even it's a combination of the two), do some **preparation to make sure it goes well**.

Here are some ideas:

- Have **tea, coffee and biscuits**
- Make sure the meeting has a **focus that people will enjoy and/or get something out of**, such as a talk from a health professional, a quiz or an exercise session
- **Share ideas for future meetings** so people go home already looking forward to the next one
- Use **membership forms** to collect people's details and get to know them better.



Getting organised

Being organised means the group is **well run** and it provides a **safe environment** for its members. It is important to **break down the tasks** to be done as much as possible so everything is done but **nobody is overworked**.

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. To ensure that individuals aren't overloaded, it is recommended the group has a **minimum of three people**: chairperson, secretary and a treasurer - if the group will have money. Ask your Volunteering and Community Officer for **Role Descriptions** for information that is more detailed.

Chairperson

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

Secretary

- Manage any paperwork
- 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 Activity 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 in by the members.

Governing Documents

It is important for a group to be clear about what its aims and objectives are. Many problems that clubs face over time can be avoided by having a clear constitution from the start. Sometimes you need a constitution before being given grant funding.

An **independent club will have a constitution** that lays down what the group will be doing and how it will run. It is also a requirement of affiliating with the Stroke Association. **Request a copy of the factsheet ‘Adopting a Constitution’** from your regional office for more information.

Voluntary groups operate under the constitution and charitable status of the Stroke Association. The group will sign the **Voluntary Group Charter**. There is guidance on how the group is run in the **Stroke Association Voluntary Group Handbook**.

Insurance

Every support group will need to have insurance cover in place in case of any claims made following an accidents or injuries.



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. Stroke Association Voluntary Groups are covered by its insurance.

Employers Liability Insurance: This is a legal requirement for any group, club or organisation that employs members of staff. Volunteers are often treated as employees in law and so it is recommend that groups have this level of cover. Stroke Association volunteers have the same insurance cover as employees.

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

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.

We recommend that Independent clubs draw up and adopt a policy. They can get guidelines and a sample policy from your regional office. In order to affiliate to the Stroke Association an independent club must have one.

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.

Equal Opportunities

Clubs or groups must be **inclusive and welcoming**. All member, volunteers and staff should feel free to be themselves and be able to make the most of being part of the club or group.

However, intentional and unintentional discrimination can happen so it's **important to have an Equal Opportunities Policy**. A policy will make clear equality is important to the club or group, builds a positive culture towards diversity and sets out what happens if discrimination does happen.

Voluntary groups must follow the Stroke Association's policy. Independent Stroke Clubs are advised to draw up and adopt a policy. The Stroke Association can provide guidance and a sample policy. An Equal Opportunities Policy is a requirement of becoming affiliated to the Stroke Association.

Finance

Stroke support groups and clubs are **self-funded**, usually through a combination of member subscriptions and fundraising activities. **Groups must keep a record of all income and expenditure.** Groups will

usually need a bank account in order to keep their money 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 startup loan for independent clubs and a £100 grant for voluntary groups. This helps with the initial costs of a new group, such as venue hire or refreshments (see 'Appendices').

The Stroke Association has no control or access over the funds of any independent club. We can give advice on finances if requested.



Voluntary groups will have a Barclays bank account opened for them that they will then manage themselves. The Stroke Association will give full training on using the card and keeping records.

Next steps for Independent Clubs

Once your new stroke support club is up and running, don't forget to tell the Stroke Association. We hold a list of all groups across the UK. Our helpline refers thousands of people every year to local groups. 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 clubs. A summary is given below. For more information, contact your regional office.

Support for you

- Free copies of **Club Together**, the quarterly newsletter for stroke clubs and groups
- Free postage and packaging on all Stroke Association 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'
- **Support** from your local Volunteering & Community Officer



Marketing your club

- Listing on the Stroke Association's website
- Specialist online software enabling your club to have professional looking **leaflets and posters printed at competitive prices.**
- Social media such as a Facebook page

Looking after members and volunteers

- Access to a tailor made **insurance package** designed and competitively costed especially for stroke clubs
- **Free criminal record checks** for volunteers

Training and events

- **Free training courses** on a wide range of subjects
- Discounted first aid training
- A **discount** on places at the annual **Stroke Club Conference**

Registering as a charity

In England and Wales, registering as a charity is usually only a legal requirement for clubs whose income is over £5,000 in a twelve-month period. Clubs whose income is less than £5,000 can continue to fundraise as a charitable group although it is advised that they adopt a constitution.



In Scotland and Northern Ireland, there isn't a requirement to register but clubs can choose to when it is right for them.

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 Contacts

UK Volunteering and Community
Partnerships Team
volunteering@stroke.org.uk
0207 566 1540

Central England
01527 903 903

Northern Ireland
02890 508 020

North of England
0161 745 8222

North of Wales
01745 508 524

Scotland
0131 555 7240

South of England
020 7940 1340

South and Mid Wales
02920 524 400

Other Contacts

Charity Commission For England
and Wales
charitycommission.gov.uk
0300 066 9197

Charity Commission for Northern
Ireland
charitycommissionni.org.uk
028 3832 0220

Office of the Scottish Charity
Regulator
oscr.org.uk
01382 220446

Volunteering Matters
volunteeringmatters.org.uk
020 3780 5870

Volunteer Now (Northern Ireland)
volunteernow.co.uk
028 9023 2020

Volunteer Scotland
volunteerscotland.net
01786 479 593

Vol Resource
volresource.org.uk

National Council of Voluntary
Organisations
ncvo.org.uk

Wales Council for Voluntary
Action
wcva.org.uk
0870 607 1666

New Club Details Form

The information given on this form will be used to update our stroke helpline database and to promote your club to callers to the helpline.

Full club name _____ Date formed _____

Meeting details

Meeting place address _____
 _____ Postcode _____

Meeting day _____ Meeting frequency _____

Opening hours _____

Transport provided? _____ Annual review meeting month _____

Activities offered

Activity	Please tick	Activity	Please tick
Carers		Support	
Creative Arts		Telephone	
Exercise		Singing	
Fishing		Gardening	
Walking		Aphasia	
Other – please give details			

Contact details

Please provide **details** of the **main contact for your club**. The Stroke Association will use this personal information to promote your club to callers to our stroke helpline. We may also contact you by post with an annual newsletter and to confirm that your contact details are up to date. For more details on how we use and look after your personal information, read our privacy policy at stroke.org.uk/privacy.

Name of **main** contact

Address

_____ Postcode _____

Phone _____ Email _____

Only provide alternate contact details if the **main contact does not want** their information on our stroke helpline database

Name of **alternate** contact _____

Address _____

_____ Postcode _____

Phone _____ Email _____

Promoting your group

We promote your Stroke Club on our stroke helpline giving callers the information you have provided on this form, including contact details. 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 details below.

I confirm that, I would like the Stroke Association to promote our club in this way. Where alternative contact details are provided, I also confirm that the alternative contact is aware of the information I have provided and the way in which it will be used.

Signature of main contact: _____

Date _____

Or, I have read the above to (name of main contact): _____

and consent was given verbally on (insert date): _____

Signature: _____ Name: _____ Job title: _____

As the main contact for this stroke club we would like to stay in touch with you.

Step 1 - Consent to stay in touch

Join our community, supporting thousands of people and families affected by stroke across the UK.

Please tick here to find out about our vital support services for stroke survivors and their friends and family, and our ground-breaking research (tick below to tell us how you want to keep in touch).

Please tick here to hear about opportunities to support stroke survivors, both locally and nationally, through campaigning, volunteering and fundraising for us, including ways to donate. We can only continue to deliver these life changing services with public support (tick below to tell us how you want to keep in touch).

Step 2 - How would you like us to keep in touch?

Please tick: Email [] Phone [] SMS []

Our promise to you

We will take great care to hold your personal information securely and never sell it to third parties. For more details on how we use and look after your personal information, read our privacy policy at stroke.org.uk/privacy

If you change your mind at any time, please phone our supporter care team on 0300 3300 740 or email: supportercare@stroke.org.uk

Support Group Start Up Funding Application Form

The Stroke Association offers startup 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 intends 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 loan is made to support 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 a start up funding, please return the form to the Community Partnerships Finance Support Officer, Stroke Association, 6th Floor St James House's, Pendleton Way, Salford, M6 5FW.

Name of your Group _____

Name of Main Contact _____

Main contact's Signature _____

Treasurer _____

Treasurer's signature _____