



START UP PACK

FOR DEVELOPING A DIFFERENT STROKES GROUP

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1. Introduction

Different Strokes aims to promote independent stroke recovery and help younger stroke survivors reclaim their lives. Our whole ethos is based around peer support, and we provide a range of services including:

- A national network of 30 exercise and peer support groups hosted by stroke survivors in their local communities, and designed to reduce isolation, regain functionality and improve wellbeing.
- Facilitating peer support via a 'closed' Facebook group with over 7,500 members that reduces isolation by offering a safe environment regardless of geographical location to share experiences and emotional support.
- Practical information leaflets in areas such as benefits entitlements, return to work, emotional support, sex, carers information, that are accessed by around 600 people per month via our website.
- An information line offering practical information and signposting, as well as the opportunity to talk to a stroke survivor.
- Keeping stroke survivors informed, through newsletters and an interactive website
- Championing the voice of the stroke survivor to Government and service providers

The groups we set up are for stroke survivors who have the desire and motivation to enhance their lives, improve their confidence and so reduce the sense of isolation. The groups are a source of support and provide stroke survivors the opportunity to share their experiences; learn from each other; and exchange coping strategies to discover new skills, and a sense of self. Although there is no official upper age limit, our groups are targeted at those who are "active" and generally of working age. This means groups tend to attract those with a desire to be proactive, and so maximize their recovery to lead a full life.

This booklet provides an outline on how Different Strokes Head Office (DSHO) will work with you to set up a Different Strokes group in your area. If after reading this booklet you would like to be involved in establishing a new group, please return the attached volunteer details form. We will then call you to have an informal conversation and talk you through how to get started.

Please be assured that we are here to support you every step of the way to ensure that your new group will be a success!

Austin Willett
CEO, Different Strokes

2. Getting Started

You have already taken the first step, by making contact with us. Once you have read these guidelines, please return the volunteer form to Caroline Saunders at DSHO, who will then get in contact with you.

Following this initial contact, the following steps will need to take place:

- Research the internet, and speak to anyone you know, to identify a suitable low cost venue for an initial meeting of the group. This should have parking, good transport links, and be accessible to people with disabilities. Often, local supermarkets provide free meeting spaces for community groups so it is worth approaching them. If there is a cost to the venue, please discuss this with DSHO.
- Research other stroke support groups in your area, checking when they meet and at what time, to ensure that you are not in direct competition with them
- Think about who can support you with a group set up e.g. friends, family, healthcare professionals and other stroke survivors.
- Form a circulation list of key people who are interested in your group. Ensure that you check with everyone that they are all ok with you sharing their e-mail address, as this may involve circulating messages to people they don't already know. **DSHO will assist with this by contacting everyone on our database in the area local to you, to see if they are interested in getting involved with the new group**

3. Meeting with Different Strokes and arranging an initial meeting

Once the initial steps have been completed, DSHO will arrange to meet with you. Depending upon your location and the timing of setting up the group, this could be one of the following:

- A training event for new groups
- A regional event for established groups, and new groups
- A 1:1 meeting, either in your location or at Head Office
- If none of the above are practical, a DSHO staff member will attend the initial meeting of your group

At this meeting we will go through the various stages surrounding the first meeting of the group – organising the meeting, promoting the meeting, running the meeting, and follow-up from the meeting. Note that if a meeting with a DSHO staff member has not been possible prior to the first meeting of the group, then these steps will instead be discussed through regular phone contact with DSHO.

Organising the meeting:

- Deciding upon the date and venue
- Liaising with people who express an interest in attending, and collating names

Promoting the meeting:

- DSHO will publicise the meeting on Facebook

- DSHO will publicise the meeting via its database
- Leaflets and posters (provided by DSHO) to be circulated in the local area, to places such as GP surgeries, hospitals; rehab units; disability advocacy groups; and any other organisation that may be able to pass on the information to younger stroke survivors.

Running the first meeting:

- Ensure you introduce yourself to everyone, and encourage other people to do the same thing, especially as you may not know each other
- Provide some background about Different Strokes e.g. the mission, vision and values of the charity
- Check with everyone about when, what time, and where the group will meet, as well as how often. How often may also depend on what time you have available to commit to the group e.g. monthly, weekly or every other week. It is useful for a group to meet regularly at the same time and same place, e.g. every Tuesday morning or last Wednesday of the month at the same venue
- Check with everyone what they hope to get out of the group, what do they hope to achieve
- Speak to everyone who comes to the meeting for ideas on what the focus of the group will be. For instance, would it be helpful to arrange a guest speaker, or will everyone take it in turns to bring up a topic to discuss.
- Ask if there are other individuals willing to volunteer their time to help facilitate the group, and/or take on a specific role within the group
- You might wish to discuss fundraising and how the group will be funded. Is there anyone who would be willing to take on this role? Would group members be willing to pay subs on a monthly, weekly, twice monthly basis?
- Ensure you get everyone's contact details from that first meeting, e.g. e-mail address, and contact number, checking it is ok if that information can be shared between group members.

Follow up:

- Send an e-mail to everyone who attended the first meeting to highlight some of the things you all discussed. Also, that you look forward to seeing them at the next meeting, with details of the location and date.
- Send everyone a reminder e-mail when the group will be meeting again about a week before.
- Encourage everyone to participate in group activities and suggest ideas.
- Continue to ask people if they are willing to take on specific roles within the group. DSHO can provide role descriptions as required

The group handbook provides extensive information on all aspects of running a successful Different Strokes group. This will be provided to you in advance of a first meeting of your group. The following sections provide a brief summary of the important points to consider in running a group.

4. The Committee

The Group Coordinator will be the main point of contact for the group and the first point of contact for new members. They also maintain contact with DSHO Office. However, the most successful groups tend to be those where there are several people involved in the running of group, and who take on various roles. Such roles could include, for example, the group coordinator, a treasurer, fundraiser, publicity and a secretary. Groups are not required to form committees, although many groups choose to do this to address key issues for group activities and fundraising, and to ensure that no single individual has to take on too large a role.

It is recommended that at an early stage you raise the possibility of other group members being part of a committee and taking on specific roles.

5. Telephone Contact

The Group Coordinator of a Different Strokes group will be listed on the website as a telephone contact. Most calls are straightforward and you may receive calls from stroke survivors and health care workers in your area requesting information about the group (e.g. the day and time you meet, activities, age of members etc.)

If the caller has not been in touch with Head Office – advise them to ring us, or alternatively, get the callers details and tell them you will pass their information onto us. Having the caller's details (name, address, date of stroke, age) means we can send out a copy of our information pack.

Do not give any stroke survivor medical advice. If a caller requests advice on any medical matters you should advise them to speak to their GP or they can call a medical helpline (e.g. British Brain and Spine Foundation – 0808 808 1000).

PLEASE NOTE - If you receive a particularly difficult call – you may refer the individual to Head Office. If you need to off load after a difficult call – please get in contact with Austin Willett or Caroline Saunders at DSHO.

6. Finances

Many groups charge a fee of £1 to £4 per person per week. For groups who provide exercise or other activities this is sometimes enough to cover the cost. Please bear in mind that fitness instructors can cost from £25.00 to £50.00 per hour, however it is possible to find well qualified instructors for £30.00 per hour. In some instances physiotherapists are willing to volunteer their time for an exercise class. Sometimes venues will also charge for this facility, however some groups find venues for free.

Once your group is established, a bank account will need to be set up with the help of DSHO. You will need at least two signatories from the group and a further two signatories



from DSHO – usually the CEO and a Trustee. However the day to day running of the account will be managed by the Group Coordinator, and/or treasurer.

Each group completes a Quarterly Financial Return which outlines income and expenditure, along with any receipts and copy bank statements, on a quarterly basis. Relevant forms to help you wish this will be supplied by DSHO once your bank account is set up. The cost of auditing the financial returns is met by DSHO.

You may also want to consider local fundraising – for example a subscription from group members, ebaying donated items, cake sales, quiz nights, approaching supermarkets like Waitrose, Asda, and Tesco's to complete a form for community matters schemes.

Any funds raised by the group in the first year up to £1000 can be used entirely for that group's services. Thereafter, the group will be required to uplift a small contribution or percentage of funds to DSHO which is relative to income and overheads. This uplift will be used to support groups with marketing materials, insurance, auditing accounts and ongoing support. On average groups contribute between 10 to 18% of their funds.

If your group has a treasurer, then they will be responsible for the group's finances. This will include keeping track of petty cash and submitting Quarterly Financial Returns to DSHO.

7. New members

Attracting new members to the group is a job for everyone. DSHO will provide you with publicity material such as flyers and leaflets, but it will be up to the group to distribute these locally to GPs, hospitals and those that you feel will be able to pass the message on to stroke survivors.

When new members from your area contact DSHO we send them an information pack as well as details of your group.

You will find that group numbers can fluctuate - some people will come every week while others will only come along every now and then or may never come back. This is natural since stroke survivors will take what they need from the group – even if it means just coming along to see what it is all about. The main thing is that stroke survivors and their carers or families are welcome and encouraged to come when they want.

Once your group is established, remind the stroke unit, early supported discharge team, and healthcare professionals that your group is meeting and check that they have displayed relevant leaflets and posters. It is also worth seeing if it is possible to visit the local stroke ward to build relationships with healthcare professionals and stroke survivors.

8. Group activities

Different Strokes groups usually set up initially to provide social support. Often with time, and through fundraising, groups move forward to provide a wider range of activities. This might be weekly, fortnightly or monthly. The following activities provided by existing groups are to offer you some ideas, rather than an expectation of what you should provide:

- Peer support
- Exercise programmes (circuit training, seated exercise, tai chi, yoga, ARNI and or tailored exercise for stroke)
- Physiotherapy
- Speech and Language therapy
- Volunteer led communication support
- Benefits advice
- Hydrotherapy
- Massage
- Reflexology
- Art Therapy
- FES (Functional Electronic Stimulation) assessments
- Guest speakers
- Social outings (meals, day trips, Xmas lunch etc.)

Sometimes it is difficult to provide an exercise class to suit all group members because of levels of mobility. This is something that a fitness instructor or a physiotherapist will be able to advise and assess. If the aim of the group is to provide activities like exercise or physiotherapy it is important to ensure that exercise professionals/ physiotherapists are appropriately qualified and have professional indemnity insurance. Guidance on this can be obtained from head office.

Refreshments are often provided when the group meets, although it is advisable to meet at a venue where tea and coffee facilities are already available e.g. a café or drinks machine.

9. Governance

Different Strokes groups are not separate stroke charities, nor affiliated clubs; they are branches of Different Strokes. This means that we are all one charity, with one charity name and number, with the same aims and objectives and governed by the Trustees of Different Strokes. Please note it is the Trustees' responsibility to ensure that our mission and purpose is achieved. They are personally liable for the conduct of Different Strokes groups and the funds raised as well as how those funds are spent and accounted for. This means that funds in the group bank account are legally the property of Different Strokes (Trustees) Limited and the Trustees provide the volunteers of the group with delegated responsibility to spend the funds for the benefit of the stroke survivors who attend the group.

The relationship between DSHO and the individual groups is governed by the Group Network agreement.

10. Support and Training

DSHO is here to help at every step, and to ensure that you receive sufficient information and support to ensure that your group will be sustainable. This help includes the following:

- Being part of the Different Strokes Charity, which promotes the needs of younger stroke survivors and their families
- Leaflets and flyers to promote the group
- Marketing materials
- Exercise guidelines
- Insurance cover (Public and Employers Liability) for group members and volunteers
- The use of Different Strokes charity name and number for fundraising purposes
- Being promoted via our information line, where stroke survivors are often referred to local groups
- Being promoted on the Different Strokes website and through the Facebook group which attracts several thousand members
- A monthly “Coordinators Update” – which provides information on training, funding initiatives, and events.
- All group members are entitled to receive an “Information Pack” on request which includes: practical information on life after stroke; benefits, what to expect from social services, the hidden side of stroke, sex and stroke, and other relevant information.
- Group members are entitled to receive a “Work After Stroke” pack on request which is particularly relevant to stroke survivors wishing to return to work or change career direction.
- Access to a “Children’s Pack” and other helpful organisations including help for parents and networking between parents
- Support with financial returns, along with DSHO paying a firm of accountants to audit and prepare end of year accounts.
- Seed funding up to £350.00 to help towards start up costs
- Opportunities to attend training events and network with other groups
- Access to Different Strokes staff to support and advise you on any issue