

Setting up a new Dystonia Society Support Group

This briefing paper provides guidance on how to go about setting up a new Dystonia Society Support Group.

Thank you for your interest in starting up a new Dystonia Society Support Group. We are delighted that you are interested. We believe that local groups are extremely important in offering support to people affected by dystonia and we could not do this without the help and support of our network of groups throughout the UK.

Groups and group volunteers are a vital part of The Dystonia Society. They are the public face of The Society locally. Groups raise The Society's profile and some raise substantial cash to help provide our services. They offer a place for local support for those affected by dystonia and help to shape The Dystonia Society's policy throughout the UK. They are also instrumental in affecting local awareness and services including diagnosis, treatment & services.

Groups can come in all shapes and sizes – they can be large or small - they can meet frequently or as little as twice a year – they can choose to handle money or not. Our aim is flexibility so that the diverse needs of members can be met.

Despite the differences there are some things we need to consider and agree on before setting up a new group. The importance of local groups cannot be overemphasised. This is why groups need to be run efficiently, effectively and in a friendly manner.

Who can become a group?

In the first instance the thing all groups must have in common is that they want to support The Society and each other. In addition for The Society to consider developing a group they must be satisfied that:

- There are initially two or more members of The society willing to meet and be welcoming to all members and staff of The Society (it is not always possible to identify a second person on your own so we can establish this when we discuss setting up a group).
- The new group will not threaten the viability of an existing group (you can see what groups are currently operating on our website by going to www.dystonia.org.uk/index.php/living-with-dystonia/groups).
- There is at least one member prepared to take on a co-ordinating role for the group (although we usually prefer 2).

If you can answer yes to these questions and would like to start a new group then please contact Group Support & Development on 0845 458 6211 or by email at info@dystonia.org.uk to move on to the next stage which is...

Becoming a group

Once it has been agreed that a group is viable the minimum requirements to become a group are that the group must:

- have at least one named co-ordinator who is prepared to be a contact for the group and take responsibility for the activities of the group. This person must go through our volunteer recruitment and screening process in order to become a volunteer with The Society.
- agree to meet at least twice a year and be welcoming to all members and staff of The Society.
- agree to raise awareness of The Society and the condition.
- agree to operate within the rules of The society

For groups that can meet the above requirements then an agreement will be prepared, signed and reviewed as required. By signing the agreement support groups become affiliated to The Society and have access to the support offered by The Society to support groups operating under the auspices of The Dystonia Society. These are:

- Use of The Society's name, logo and registered charity number.
- Financial support where feasible.
- Access to Group Support & Development.
- Fundraising support from the Fundraising Team.
- Information and advice from the Helpline Team
- Free access to Society literature (ie leaflets, posters and other printed materials such as letterheads etc).
- Regional forums for groups and volunteers.
- National publicity for events and activities.
- Dispatch of Group mailings and newsletters.

Remember if you would still like to discuss the possibility of setting up a new Dystonia Society Support Group in your area please contact Group Support & Development on 0845 458 6211 or by email at info@dystonia.org.uk.