



OPERATING RULES

FOR

THE DYSTONIA SOCIETY SUPPORT GROUP NETWORK

MAY 2012

Background

The Dystonia Society greatly values the role of volunteers in running the groups locally. The contribution they make to the work of the organisation is huge. The Society believes that, as far as possible, groups should be free to operate as they determine to be appropriate. It is recommended that groups stay in close contact with Dystonia Society staff to help them run as effectively as possible.

However, there are a number of charity rules, other legislative rules and good practice requirements that everyone operating within the Dystonia Society including volunteers need to follow. These are laid out below. The Trustees and staff of the Society have an obligation to ensure that all activities, including those of groups, adhere to these rules. The purpose of this document is to ensure the Society meets this obligation.

Some of these rules may seem like common sense but our group volunteers come from a wide range of backgrounds and with diverse levels of experience. To ensure that we all have a common basic knowledge it is important that as an organisation we put these rules in writing to ensure everyone understands them and all agree to them.

In order to use The Dystonia Society name and fundraise using The Dystonia Society charity number, all groups must commit in writing to follow these rules. Minor additions or amendments to the rules will be considered on a group by group basis. Groups should contact Group Support staff if they would like to make alterations or amendments to the document for their group.

The Society's website contains more detail and guidance on the rules included in this document and groups should refer to these pages if they want more information about why a rule has been included or are unclear on anything or they may contact Group Support staff if they need further guidance.

In addition, The Dystonia Society has some overall goals that it needs to achieve in every part of the UK. These are:

- To provide a forum for people with dystonia and their carers to share experiences.
- To raise awareness of the Society in neurology clinics and elsewhere.
- To work together with the Neurological Alliance and other neurological organisations locally to achieve the Society's goals.
- To raise funds (small or large events – they all make a difference).

We would urge groups to get involved in these activities if at all possible. However, aside from the minimum requirements listed below, it is the decision of the groups whether they wish to do so.

Group Activity

All group activity must be directed towards the objects of the charity which are:

- to promote the welfare of those persons suffering from the movement disorder known as DYSTONIA or from similar or related conditions; and to advance the education of the public about all aspects of these conditions.

Each group must hold a minimum of two meetings per year and do at least one awareness raising project annually. Meetings should be publicised in Dystonia Matters (and in the Scottish newsletter for Scottish groups) and on the website. Ideally each group should also send out a minimum of one mailing per year to the members in their area (this can be organised through UK Office). If groups choose to produce a newsletter for members (this describes anything other than a letter containing factual details about upcoming meetings) they must include a disclaimer which states "The views expressed in this newsletter are not necessarily the views of The Dystonia Society unless expressly stated otherwise". Each group should report on activity to UK Office at least once a year. Mailings done through UK Office should be sent to UK Office at least 4 weeks before the mailing needs to arrive with the members.

Accessibility

The group should be open to all affected by dystonia irrespective of gender, age (above 18 yrs), ethnicity, sexuality and disability. All new members should be properly welcomed.

Standards of Behaviour

The group is entitled to expect a reasonable standard of behaviour from all attendees including but not limited to being willing to listen and not dominate the conversation to a level where other people feel excluded, not being prescriptive or diagnostic about people's conditions, not interrupting, not being aggressive, not drinking excessively or being under the influence of illegal drugs. In addition all group members need to be aware that they are not medically qualified and that their personal experiences may not be representative of others with dystonia. A group is entitled to exclude any person who fails to adhere to standards after due warning. The group coordinator should discuss any exclusion with Group Support staff, before acting. It is recommended that each group agrees a short list of standards of behaviour that can be referred to in the case of any issue.

Group Coordinators

Each group must have a coordinator. Their role is to act as a link to UK Office and ensure that the group adhere to the rules of this document. All coordinators must be members of the Society. The Society will take up references before allowing any person to become a coordinator. Group coordinators should be willing to attend occasional forums and training organised by The Dystonia Society. Groups are perfectly entitled to use an alternative title for their group coordinator (eg Chairperson), however the Society will refer to this position collectively as group coordinator. It is up to the group to notify UK Office of the name (and alternative title if there is one) of their group coordinator.

Group Volunteers

The group coordinator must refer all new group volunteers, who take on a regular (eg are allocated an 0845 number, look after the groups money etc) or decision making role with the group or represent the group externally, to Group Support Staff for screening. If the group coordinator is in doubt about whether a volunteer needs screening they should contact Group Support staff to discuss. The group coordinator must also advise UK Office of any group volunteer changes (eg when a volunteer stops being a volunteer).

Decision Making

Decision making should be inclusive of the whole group, including a vote if necessary, and not limited to a few individuals. However, groups can delegate some decisions to elected officers provided this is properly organised and minuted.

Gifts

Small items such as chocolates, biscuits or a bottle of wine may be accepted on behalf of the Society and such gifts can be used as raffle prizes or can be shared if appropriate. Small gifts can also be accepted as a token of appreciation. In order to protect both the group and the Society valuable gifts offered should be discouraged. If a raffle prize with a value in excess of £100 is offered please contact UK Office to discuss the matter - it may be possible to make more of the prize nationally or with national support.

Health and Safety

No background checks are made on attendees or presenters for groups. Therefore, the group needs to be careful to keep the event safe by using the following rules:

- Group events should be held in a suitable and accessible public place and not in a group member's home (if any group wishes to make an exception for an individual event such as a barbecue they should agree in advance with Group Support staff and ensure they have appropriate insurance).
- No person under 18 should attend group meetings unless accompanied by a responsible adult. Groups should notify Group Support staff if they have any concerns.
- Never make home visits and only meet in public places.
- Ensure that no remedies or medication are offered, available to take or handled at group meetings.
- Ensure that any person presenting therapeutic information who is not either a qualified medical professional (such as a doctor, physiotherapist or nurse) or an employee of the Society shows proof of public liability insurance prior to the meeting. This includes counsellors, homeopaths and other complementary therapists. .
- If a therapist is presenting the following disclaimer should be communicated to all attendees: "We are very pleased to welcome XXX to the meeting. However, The Dystonia Society have not evaluated this therapy and cannot take responsibility for any outcome. Members participating in complementary therapy sessions do so at their own risk".
- Groups should undertake the Society's simple risk assessment (available on the group pages of the website) when proposing/planning events which are outside the norm. For example when a speaker/therapist will offer "tasters" of the therapy they are presenting or when a meeting is to be held in a new venue or private home. Groups should discuss the assessment with Group Support staff before proceeding.
- Groups should discuss any potential events/activities that may operate outside these simple rules with Group Support staff before proceeding.

Online

The Dystonia Society website has a page for each group which will be updated promptly upon a request being made to UK Office. As the website has more than 150,000 visits per year it is the most effective way to reach people. If a group wishes to run a website they should advise Group Support staff and medical information and videos must be approved by UK Office in advance. Groups must not run website forums but can set up a thread on The Dystonia Society forum. Blogs must be personal and not published under The Dystonia Society name.

Phone Numbers

Personal phone numbers must never be used as the contact number for the group. This should always be an 0845 number allocated by the Society.

We do, however, recognise that on occasion it is necessary for a mobile number(s) to be made available for the effective coordination of group events and activities. This may be done as long as the volunteer is fully aware of the potential risks involved (eg nuisance calls, late night calls etc). The number should not be publicised in places outside of the group (eg Dystonia Matters, Online, Group newsletters etc). As an alternative groups may either have their 0845 number redirected to a mobile for convenience or have a second 0845 number they use for this purpose and have redirected as required.

Emails

The Society is not currently able to provide groups with email addresses. It is recommended that groups set up a separate account such as a "gmail" or "hotmail" address to use or alternatively use a private email address, if the volunteer is comfortable with this. The group coordinator should advise UK Office of any email address being used by the group for contact by members.

Data Protection

Strict laws govern the holding of information about other people. It is recommended that, as far as possible, personal information is not held by groups and that mailings are organised through UK Office. If your group needs to hold personal information you must contact Group Support staff to discuss how this will be managed for your group to ensure data protection legislation is complied with. If personal information is held, the following rules apply:

- The information is held only by those who need to know for the effective operation of the group and must not be shared generally with members of the group.
- The information must be kept up to date and accurate.
- The information is used only for the operation of the group and must never be shared with third parties.
- The information must be password protected (this includes USB sticks) and kept in a locked place.
- The information must be destroyed immediately it is not needed (for instance if someone leaves).
- Due care must be taken in transporting hard copy information (for instance lists must not be left lying about).

Confidentiality

Any information provided on an 0845 number or to a group must be treated as confidential and not shared with anyone other than employees of The Dystonia Society. Group volunteers should take care not to be overheard when taking 0845 calls. The only exception to this policy of maintaining confidentiality is when the information indicates a threat of significant harm to self or others (e.g. through potential suicide, self-harm or violence) or a potential criminal act. In this case the police should be informed on '999' immediately and the helpline (0845 458 6322) at the first opportunity. If there is any doubt at all, the police must be called.

Giving Support

Giving support is one of the most important roles local groups can play. However, all group volunteers need to be aware that they are not medically qualified and that their personal experiences may not be representative of others with dystonia. They therefore need to be careful to adhere to the following guidelines:

- It is fine to listen empathetically to someone else's experience and describe your experience.
- But you must not make diagnoses, provide information or advice on dystonia, give advice about treatment or recommend treatment centres.
- Remember that criticism of named individuals or organisations could be defamation and have legal implications.
- If in doubt you can refer people to The Dystonia Society helpline (0845 458 6322) or website (www.dystonia.org.uk).
- If group volunteers become distressed or upset as a result of providing support they can contact the helpline for support or contact Group Support staff in England or Scotland.

Vulnerable Adults

People with dystonia in receipt of local authority support are designated 'vulnerable adults'. If anyone involved in the Society becomes aware of abuse of such people we have a legal obligation to inform the local authority within 24 hours. Abuse in this context can include physical abuse, financial abuse such as theft or coercive borrowing, psychological abuse such as bullying. If group volunteers become aware of such abuse they should report it to the group coordinator who should report it as soon as possible. Within working hours this can be done via the helpline on 0845 458 6322 but outside of working hours and at weekends the group coordinator should refer the case to the out of hours social services department at the local council.

Finance

The rules governing charity finance are strict and groups need to be aware of them. We have a duty to present a complete and truthful picture of all the money raised in the name of the Society, the purpose for which it was raised and how it was spent.

Basic principles:

- All groups must operate with the intention of being self financing.
- Groups may not carry forward at the end of the financial year in excess of £500 in their individual account, unless otherwise agreed.

Banking: The safest approach is for The Dystonia Society to hold group funds. This is a requirement for all new groups. Current groups are urged to transfer their banking to the Society. If a group decides to keep their own account, they have an obligation to ensure funds are used in accordance with Society rules, that records are kept of all receipts and payments and bank statements must be checked by at least two people. References will be taken for all signatories and the CEO must be a signatory.

Expenses:

- The single item limit is £250 and the limit per event is £250 (unless agreed in advance with Group Support staff).
- Funds must only be used for running the group and may be spent on administrative costs (venue hire; postage and packing; newsletters; refreshments etc), facilitating social contact through events and transport costs (where severe dystonia prevents someone from attending a meeting).
- Local group funds must not be used to purchase equipment for people affected by dystonia; alcohol and branded materials.
- Large invoices can be sent to UK Office with a cheque/BACS requisition.
- Personal expenses can be claimed using Society expense claims forms with receipts attached.
- No payment will be made if the group account has insufficient funds.

Petty Cash Float:

- Each group may operate a petty cash float which must not exceed £100. This must be held by a designated and screened volunteer in a lockable tin.
- Records must be kept and it must be reconciled regularly and always before it is topped up.

Raising money: Groups are free to raise money with the following exceptions;

- Groups must not approach any charitable trusts or large companies without first discussing the matter with the Fundraising Team.
- If a group wants to undertake a public fundraising event they should seek advice early from the Fundraising Team.

Cash receipt handling: Two unrelated people (who must be members of the Society) and who do not live at the same address must always be present to count, record and check the money. A cash count form must be completed. A standard form is available with guidance.

Annual Financial Summary/Reporting: All groups must send a simple Annual financial return to UK Office by the end of April (for the period April - March). This must be accompanied by a copy of their annual accounting records showing all money raised and spent during the financial year which is supported by receipts and details of income. Even if there is no money raised or spent a return must still be sent confirming this. A standard form is available with guidance.

Allocation of funds: All groups with over £500 at the end of the financial year must complete an allocation of funds form. This form enables groups to allocate any excess funds they have raised to one of a number of important areas of work identified by the Trustees. Groups must return this form to UK Office by the end of September for action otherwise the Trustees will make the allocation.