

# Ataxia UK Support Group Guidelines



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Ataxia UK  
[www.ataxia.org.uk](http://www.ataxia.org.uk)  
Helpline: 0845 644 0606

Ataxia UK works across the whole of the UK and is a charity registered in Scotland (no SC040607) and in England and Wales (no 1102391) and a company limited by guarantee (4974832).

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**“It allows you to talk with others, to discuss problems and situations. The social aspect is brilliant!”**  
**Dave, Peterborough**



Congratulations! You're thinking of setting up a support group of Ataxia UK, and we are here to help you every step of the way. Ataxia UK's groups and branches provide essential support, and we couldn't run them so well without people like you. Between 2006 and 2009 our network grew an amazing 300%! Local representation is vital to the development of Ataxia UK, providing personal support, increased publicity and influence, and opportunities for fundraising.

Being a support group is different to being a branch – branches are a formal representation of Ataxia UK. Support groups are very informal; they provide support, information, raise awareness, meet regularly and have social events. Individual members of support groups can fundraise for Ataxia UK.

By setting up a new support group we are able to support people with or affected by ataxia on a more local basis, helping to reduce the isolation that is so often felt by people with the condition.

However, to be a group we ask that you agree to a few Dos and Don'ts that we all have to stick to - we have explained them clearly and kept them to a minimum.

We will update this guidance from time to time. If you would like any further support, it's yours for the asking. Just contact the Branch Development Manager.

We don't for a moment underestimate all the hard work that goes into running a successful support group, so thank you.

## We want to set up a support group - what next?

### Who is the main contact for this group?

You need to have one or two people as the main contact for this support group.

### Do you have contacts for other potential members?

If you put together a letter to potential new members head office can identify people in your area and then send the letter for you.

### Do you have a venue to meet regularly?

It is a good idea to identify a venue where members can meet. This could be in a pub, hotel lounge, community centre, church hall or in your home - it's up to you. Then at your first meeting you can discuss and arrange further venues.

### How often will you meet?

Members of support groups support each other via the phone and email and meet face to face at least once a year.

### Do you have a plan for the social activities that you might like to arrange?

From past experience, support groups enjoy meeting together and therefore it's a good idea to have some sort of plan about possible social activities you could arrange for your group.

## Basic Standards for Support Groups

To be a support group there are some things you must do:

Have a named person as contact for the group with address and telephone (and email contact if possible)

Send group contact details with your welcome letter to new potential members

Keep an up to date list of members on the supplied form which must be sent to the Branch Development Manager twice a year in January and July

Meet at least once a year for social activities and support

You must carry out the above things as a minimum however your group can meet more often and do more than this – it's up to the group to decide.

The Branch Development Manager will offer support to enable support groups to offer these basic standards. The basic standards may also change from time to time.



These are some other things you might like to do:

Send out a newsletter at least once a year to all members

Carry out some press work to publicise your group and ataxia

Although support groups are not legally part of Ataxia UK, they are a really important way to support people locally and play a large part in our mission as a charity.

**Ataxia UK's mission is:**

We fund research into developing safe, effective treatments. Our ultimate goal is to find a cure for ataxia.

We help people to live with ataxia in the meantime by assisting them to access the best care and support available, to enable them to achieve the highest quality of life open to them, and by providing a range of services that are not available anywhere else.

We aim to support all people affected by ataxia; people with the condition, their families, carers, friends and colleagues.

## Responsibilities

Your group represents Ataxia UK therefore you have certain responsibilities that you must follow:

To ensure confidentiality of member's details or information that they may disclose - see section on data protection.

As a support group you can hold meetings and social events in order to offer support to your members.

**Individuals** may raise funds for Ataxia UK.

You must not undertake any activity that is likely to bring Ataxia UK into disrepute.

Support Groups *must not* at any time use:

- Telephone canvassing
- Chain letters
- High volume e-mails
- High volume text messages



**“It gives me a chance to meet new people and others who are affected by ataxia so I can appreciate all the things I do more. You can forget about life, briefly.”**  
**Chris, North Wales**

Support groups **must** let Ataxia UK know beforehand if individuals are thinking about any of the following:

- Running bingo, lotteries, raffles or other or other gaming/gambling events
- Making a broadcast appeal
- Employing professional fundraisers, even on a casual basis
- Operating charity shops or having a stall in a public place such as a public market
- Promoting or advertising a particular commercial enterprise in return for a donation or consideration.

Merchandise is available for individuals on a sale or return basis, please contact Head Office if you would like some or other fundraising or awareness materials.

There are lots of fun and easy activities individuals can do to fundraise for Ataxia UK - contact Ataxia UK's Fundraising Manager for further help.

## What support groups can do:

Meet socially for mutual support

Organise social events

Raise awareness of ataxia and Ataxia UK

Members can individually raise funds for Ataxia UK

Offer telephone/email contact for members

Produce a newsletter

Please contact the Branch Development Manager if you have any queries.



**“We refer to the guide, and if any issues arise, the Branch Development Manager is there to answer any queries.”  
Katie, London**

Ataxia UK will ensure that:

Help is available with the setting up of your support group.

The Branch Development Manager will meet with you to go through this guidance and answer any queries you have.

All queries will be responded to as quickly as possible.

Continuous support is available for your support group.

We hope you set up a successful support group and enjoy many social events with your members.

Please contact your Branch Development Manager if you have any concerns or queries.

Your support group may also be set up as a 'satellite' support group - this means that you are part of an existing branch.

Branches sometimes find that, because they cover a wide area, some people cannot attend branch meetings because it's too far for them. In this instance setting up a satellite support group is a great idea as it allows those people to meet and support each other.

Satellite group members are still members of their branch and should be involved with branch activities and events.

Whoever runs the satellite group will be on the committee of their branch.

The branch will keep the satellite group members up to date with branch activities.

The satellite group coordinator will run the group in accordance with the branch Chair, this guidance, and Ataxia UK instructions.



**“Just being involved is fun!”  
Dave, Peterborough**

### **Finding a venue**

Finding somewhere to meet on a regular basis need not be too difficult. You can try the following places:

Local library, schools, Church hall, Community centre, Health Centre, Hotel Lounge, Hospital, local Voluntary Services Council (they often have rooms you can use or can inform you of rooms that are available from other organisations), Sheltered Accommodation Community Rooms and Civic Centres.

Ask your members if they know of local places that you can use.

### **Health and Safety**

You need to be aware of disability access and any problems that people with mobility problems or in wheelchairs may come across in the venue you are considering. Health and safety must be taken into consideration whenever you are using a venue for regular meetings or an event. Health and safety of the venue would be the overall responsibility of the person who owns it or is in charge of the rooms they are allowing you to use. If you think something is a health and safety risk you must bring it to the attention of the person who owns the venue or is in charge of it.

If you are unsure about the responsibility of health and safety please contact the Branch Development Manager.

## Data Protection

**“It’s good to meet others with similar conditions.”**

**Marta, Derby**

Whatever information you hold about people, most of it will be subject to the terms of the Data Protection Act. This means you are not allowed to disclose personal information to any third party without the permission of the person that the personal information belongs to. Unless Ataxia UK advises you otherwise, all personal information is covered by the act.

The 1998 Data Protection Act is concerned with 'personal data'.

Personal means information about an identifiable, living individual: You can work out who the person is from the information you hold, such as a name, a photograph, a membership number or postcode. Living -but in some circumstances the Act applies to people who have died. Individual - this includes individual contacts listed under the name of an organisation e.g. the landlord of your local 'fundraising' pub or a supplier.



Data means:

Information held on computer e.g. a computer database

Information in a 'relevant manual filing system' e.g. any paper based records, including address books and diaries - depending on how the information is recorded

Information intended to be held on a computer or manual file.

A relevant filing system means any set of information relating to individuals, which is structured either by reference to individuals or a criterion relating to individuals, in such a way that specific information relating to an individual is readily accessible. For example:

conference or event booking forms

fund raising/donor forms

newsletter mailing lists

computer -based records of branch officers and volunteers

an address book, including your email address book

application forms filed in alphabetical order

records filed by membership number (where another file exists giving name and address etc. relating to that membership number)

picture library of photos filed by name

Legal responsibility for complying with the Act lies with the Data Controller, Ataxia UK. Branches must work within Ataxia UK's policies, they cannot decide for themselves why and how personal data is processed. If they do, they will be legally liable for that data and could be open to prosecution if found to be in contravention of the Act. Branches, and Ataxia UK staff, are and should remain 'data processors', working strictly within the guidelines set out by this guide.

Please contact the Branch Development Manager if you are unsure about your responsibilities in regards to data protection.

