



## Support Group Leader Volunteer Description

Ataxia is an umbrella term for a group of neurological disorders that affect balance, co-ordination, and speech. There are many different types of ataxia that affect people in different ways. Ataxia is a rare condition, with approximately 10,000 adults and 500 children living with a progressive form of ataxia. Ataxia UK is the only leading national charity for people affected by any type of ataxia. We fund research into finding treatments and cures, and offer advice, information, and support to people affected by the condition.

**Volunteer Role:** Support Group Leader Volunteer

**Supported by:** Branch & Support Group Leader Co-ordinator and the Services Team; Community Programme Officers

**Where:** Area dependent/ online over Zoom

**Commitment:** We would like you to be able to volunteer with us for at least 1 year, and able to volunteer for at least 1 day per month

**Training:** As part of your volunteer onboarding - Equality & Diversity Training, Safeguarding, Health & Safety, How to use Zoom

### **Objectives:**

Local groups across the UK are run by volunteers and offer friendship and support to people living with ataxia, their families and friends.

We are looking for a Support Group Leader to help us support and lead a support group in the specified geographical areas.

We have more than 50 Branches and Support Groups who meet regularly both online and in person supporting 100's of Friends of Ataxia UK.

Ataxia UK, 12 Broadbent Close, London N6 5JW Office 020 7582 1444 Helpline 0800 995 6037  
volunteering@ataxia.org.uk

www.ataxia.org.uk Ataxia UK is a Charity registered in Scotland (SC040607) & England & Wales (1102391); & Limited Company (4974832)

### **The skills you need:**

- Lived experience of ataxia (as diagnosed with or as a family or friend affected by ataxia)
- If diagnosed, to have been so for at least 1 year or have been a Friend of Ataxia UK for at least 1 year
- Willingness to learn
- Be knowledgeable and friendly when representing Ataxia UK
- Good interpersonal skills
- Are committed and reliable
- Willingness to travel around where you live
- Be a good communicator, as you will be working with a wide range of different people

### **What you will be doing:**

- Be first point of contact for those enquiring about a support group in their area
- Signposting new members of the group to the Ataxia UK Helpline as needed
- Keep up to date about the news and developments of Ataxia UK, and actively share them with the group (e.g. e-newsletter/by email)
- Alongside support from the Services team, source appropriate venue for support group meetings
- Organise and book (in person/ Zoom) meetings
- Work with group to set dates & an agenda for support group meetings
- Actively lead regular meetings either online/in person
- Represent the ataxia community and Ataxia UK at a range of different events in your area (if applicable)
- Network and foster good relationships with organisations, healthcare professionals or researchers in your area and with those that enquire about Ataxia UK
- Attend quarterly supervisions with Regional Support Group Leader Co-ordinator and supervisions with the Services Team
- Be motivated and reliable, and able to show patience and empathy when dealing with sensitive situations
- In this role you could be handling personal or sensitive data, and so by undertaking this role you may need to undergo continuous data protection and other training.

### **In return, as an Ataxia UK volunteer, we will offer you:**

- Induction learning
- Great addition to your CV
- Make a real difference for people living ataxia

### **For further information, please contact:**

- [volunteering@ataxia.org.uk](mailto:volunteering@ataxia.org.uk)

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