



Multiple System Atrophy Trust

Support Group Leader Role Description

About the Multiple System Atrophy Trust

We are the UK's main support and information service for people who have multiple system atrophy (MSA) . a rare neurological disease with no known cause or cure. As well as helping people who have MSA, we are also there to support families whose lives are affected by MSA as well as carers and health and care professionals who look after and treat people with the disease. We do this by providing:

- MSA Nurse Specialists with specialist knowledge of the condition who offer support, advice and guidance
- Support services including a telephone and email advice service and an online forum
- A network of volunteer-led Support Groups located around the UK
- An online MSA Local Hub designed to harness community knowledge and to offer more support at a local level
- Education and support for health and care professionals to help them provide the best possible care and treatment for people with this rare and complex disease

The Trust was formed in 1997 (originally called The Sarah Matheson Trust . renamed to Multiple System Atrophy Trust in 2010) and our Vision is a **World Free of MSA**.

We are committed to making this happen by funding research to find the cause of, and one day a cure for, MSA.

The facts on MSA

- Multiple system atrophy (MSA) is a neurological brain disease that leads to premature death
- Its cause is currently unknown
- It is random and can affect any one of us
- Its effect on the individual, their family and carers is devastating as the disease impacts on a person's mobility and ability to communicate
- About five in every 100,000 people are affected by MSA and there are up to 3,300 people living with MSA in the UK

- Symptoms usually start between 50 and 60 years, but can affect people younger and older
- There is currently no known cure

Involving volunteers in our work

People with MSA, their families and carers live in cities, towns and villages around us. It is vital that we provide support to them and raise awareness of MSA to help tackle the isolation felt by having a rare disease.

That's why volunteers are so important to our work. Our volunteers help us to support families affected by MSA, raise awareness of MSA within local communities and increase the knowledge of health and care professionals so that they can provide better and more timely treatment and care.

As a charity funded entirely by donations from individuals, companies and charitable trusts, local volunteers also support us by raising vital funds to allow us to continue our work.

What this role involves

Support Groups provide essential help to people affected by MSA. Local Support Groups bring together people affected by MSA in an environment of mutual support and friendship, and help to tackle the sense of isolation felt by having a rare disease. This role involves:

- Organising around three group meetings per year. There is no set timetable for meetings, organisation and the agenda are usually set by group leaders and participants based on local priorities
- Responsibility for arranging a suitable venue for the meetings, taking into account practical aspects such as accessibility needs, numbers attending, ensuring venues have adequate insurance and there are suitable health and safety procedures in place*
- Responsibility for providing light refreshments for meetings and organising activities such as raffles*
- Contacting local professionals and organisations to speak at the group meetings in order to provide members with useful information
- Liaising with our Office team and MSA Nurse Specialists to set meeting dates and help us to promote the Support group in your local area
- Providing feedback to the Trust about the group and main topics arising
- Adhering to the Trust's relevant policies and procedures
- Opportunities to get involved in other areas of the Trust's work, such as supporting with events

**All pre-agreed meeting costs incurred will be met by the Trust directly*

We are open to this role being shared between a couple of people so if there are two or three of you willing to share this role then please do get in touch with us.

The benefits that you'll receive

All of our volunteers can expect to be welcomed and made to feel part of the wider volunteer network. Through volunteering with the Trust you can look forward to:

- The opportunity to gain experience of working within the charity sector
- Taking on a challenge and meeting new people
- A thorough induction to the Trust and the volunteer role. You will receive a copy of our Volunteer Handbook to help get you started and Support Group Leaders will also receive our Guide to Running Effective Meetings manual.
- All pre-agreed out-of-pocket expenses reimbursed in line with our Volunteer Expenses Policy
- A Volunteer Newsletter three times a year and our MSA News magazine.

Skills and experience required

We are committed to equal opportunities and welcome applications from all sections of the community. You don't need to have any experience to volunteer in this role, but you should have a basic understanding and knowledge of MSA and ideally you should be able to demonstrate:

- Good interpersonal skills
- Reliability and honesty
- An ability to work as part of a team
- Good organisational skills

How to apply

If you are interested in applying for this role, please contact us on **0333 323 4591** or email **volunteer@msatrust.org.uk** for further information and to request an application form.