



# Multiple System Atrophy Trust

## Volunteering Handbook



***Our volunteers are at the heart of our work and at the heart of every community so that people affected by MSA receive the support they need***

# Thank you

Volunteering is an immensely valuable gift which allows us to ensure that people affected by MSA receive the support they need. We are grateful that you have chosen to give your time to support our cause, thank you.

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.

Volunteers are so important to our work. People help us to signpost 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, volunteers also support us by raising vital funds allowing us to continue offering our services and fund research.

The purpose of this handbook is to give you some information about the Trust and to provide you with a good understanding of your role as a volunteer. It also highlights guidance on key policies that may be relevant to your role, and provides reference on where to find further information.

## Contents

<b>About the Trust</b>	<b>3</b>
<b>The facts on MSA</b>	<b>4</b>
<b>Our services</b>	<b>5</b>
<b>Working with volunteers</b>	<b>7</b>
<b>Supporting volunteers</b>	<b>8</b>
<b>Health and safety</b>	<b>10</b>

We want to ensure that your time volunteering with us is both rewarding and enjoyable, and we will do all that we can to support you in your role.

***Thank you again for choosing to volunteer for the Multiple System Atrophy Trust.***

## About the 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 also support families whose lives are affected by MSA and health and care professionals who look after and treat people with the disease. We do this by providing:

- MSA Nurses Specialists with expert knowledge of the condition who offer support and guidance
- Support services including a telephone and email service, our MSA News magazine and our website which include an online forum
- A network of volunteer-led Support Groups located around the UK
- A range of fact sheets and information guides
- An online MSA Local Hub 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.

To ensure our services are accessible to everyone, the Trust is committed to providing its services free of charge. We are a charity funded entirely by voluntary donations from individuals, companies and charitable trusts.

The Trust is managed by a Board of Trustees who meet on a regular basis. The Scientific Advisory Panel ensures proper and fair allocation of research funds. The Trust's services and information is reviewed by a committee comprising of MSA Nurse Specialists, medical staff, Trust staff and people affected by MSA.

# The facts on MSA

Multiple system atrophy (MSA) is a rare, degenerative neurological disease that affects adult men and women and is life-limiting. It is caused by the shrinking (atrophy) of nerve cells in multiple areas of the brain which results in problems with movement, balance and automatic functions of the body such as bladder and blood pressure control.

- 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 and Ireland at any one time
- Symptoms usually start between 50 and 60 years, but can affect people younger and older
- Some people with MSA say it feels like the disease is trapping them in their own body
- There is currently no known cure.

## Our services

Alongside our work, we also fund research projects looking into the cause of MSA, with the hope of finding a cure.

The services we provide include, but are not limited to:

### MSA Nurse Specialists

Because MSA is not common, some health and care professionals may meet somebody with MSA only once or twice in their whole career. A vital part of the Trust's information and support service is, therefore, its nursing service provided by our MSA Nurse Specialists.

Our Nurses support people affected by MSA across the UK and Ireland to help reduce isolation and give vital symptom management advice. They are available by phone or email five days a week, attend MSA clinics, Support Groups and train health and care professionals.

### Support Groups

Many people gain support from getting to know others in a similar situation to their own – whether they are carers, family members or someone with MSA.

Finding somebody else who has an awareness and understanding of the challenges a rare disease brings, can also help break down barriers and the sense of isolation some people feel.

We know that attending a Support Group is not always possible, perhaps because of distance or practical issues in getting to venues. Some people enjoy attending group meetings whilst others prefer accessing the Support Group community online. The Trust therefore has two types of groups to try and meet these different needs: a virtual support community provided through our forum on the website moderated by our MSA Nurses, and the more traditional format of regional Support Groups held across the UK and Ireland which are run by our volunteers. We also have a HealthUnlocked community which our staff moderate and offers people a chance to share helpful tips and experiences - <https://healthunlocked.com/msa-trust>.

### Fact sheets

Created by our Information and Support team, with input from health and care professionals, people with MSA and carers, we have produced a wide range of clear and informative fact sheets to guide families on adapting to life with MSA.

We are accredited by the NHS England Information Standard which indicates that our information resources are up-to-date and reliable.

## Magazine

The MSA News magazine shares stories of real people finding their way from diagnosis onwards, including issues covered across our growing network of volunteer-led, regional Support Groups. Our MSA Nurse Specialists write articles on symptom management and treatment. It also highlights the dedication of our members to supporting the Trust's work through committed and imaginative fundraising.

## MSA Local Hub

The MSA Trust's Local Hub is a resource tool developed to provide information about services relevant to people affected by MSA. It captures the spirit of the MSA Support Groups by sharing local knowledge and information to help a greater number of people.

Our members can search for local services that other people affected by MSA, or their carers, have found helpful.

The list of services is created with input from our members, who supply the Trust with the information. It is a way of 'tapping' in to the vast amount of knowledge built up by our members. The MSA Local Hub can be found on our website - [www.msatrust.org.uk](http://www.msatrust.org.uk).

## Research

We are the main funder in the UK of research into multiple system atrophy. Our vision of a world free of MSA is our aspiration and ultimate goal. To achieve this we are committed to funding the best scientific research.

*"The Trust's vision, aspiration and ultimate goal is to one day find a cure for MSA, a sentiment shared by our members who tell us they see this as a key priority for the charity. We are committed to spending a minimum of £150,000 on research every year and hope, as funding allows, to increase this still further."*

Professor David Burn, Trustee and Chair of the Trust's Scientific Advisory Panel

To ensure we are funding the very best research we comply with the criteria laid down by the research standards body, the Association of Medical Research Charities (AMRC). Our independent Scientific Advisory Panel carefully scrutinises all grant applications.

MSA is an extremely complex disease that is difficult to diagnose, and research to find the cause and ultimately a cure may take many years. However, every research project we fund takes us one step closer.

# Working with volunteers

Our volunteers are at the heart of our work and we are incredibly grateful for the contribution made by each of them. We are committed to ensuring you receive the best possible experience whilst volunteering with us and that you feel fulfilled and valued.

## What we look for in volunteers

We are proud of our achievements as a charity and your contribution helps us to achieve our success.

To support our work we need volunteers who have a genuine interest in supporting families affected by MSA and are committed to helping us fulfil our Vision to have a **World Free of MSA**.

## Mutual expectations

- or you no longer wish to continue volunteering with us  
Volunteering is a gift relationship and we are extremely grateful to volunteers for offering their time freely and willingly. We don't ask volunteers to enter into a contract with the Trust, but to make sure you enjoy your role we do make a commitment to you to:
- Provide a thorough induction on the work of the Trust, a clear idea of your responsibilities and support to help you carry out your role
- Provide a named person to guide and support you, offer fair and honest feedback and updates on how your work has made a difference
- Have an open approach to receiving feedback from you – good or bad – to allow us to improve what we do
- Treat you with respect, consideration and appreciation.

In return, we ask you to:

- Commit to our aims and values
- Respect others regardless of backgrounds, characteristics, ideas and beliefs and act in a professional way when representing us in public  
Commit to the requirements of your volunteering role and provide as much notice as possible wherever this isn't possible,
- Abide by the Trusts policies and procedures, including data protection and confidentiality
- Understand the boundaries of your volunteer role and abide by these.

## Time commitment

How much time you give to volunteering depends on your role and role description. We acknowledge that some roles will require more or less time and will discuss this on an individual basis.



# Supporting volunteers

All of our volunteers have a nominated member of staff or volunteer to offer guidance, support and advice. You will be informed during your induction who this person is and we will always make sure you are kept up-to-date with any changes to staffing or contacts within the Trust.

## Training and development opportunities

Training and development of volunteers is integral to all roles. Upon joining the Trust you will receive a thorough induction and be made to feel as welcome as possible. You will be properly briefed about the responsibilities of your volunteer role and given all the necessary information to ensure you receive the best possible experience.

We are happy for Support Group Leaders to book themselves onto a half or full day basic first aid course which we will then reimburse the costs of.

## Regular contact

We feel that regular contact with you is vital to ensuring your time with us is both rewarding and fulfilling. This is a two way process and, as a minimum, you can expect from the Trust:

- to receive a regular volunteering newsletter
- invitations to any events in your local area
- encouragement to look for ways to facilitate networking with other volunteers
- invitations to participate in annual volunteering reviews
- news and updates from the Trust.

As a volunteer we would like you to:

- meet any reporting requirements of your role and keep us up-to-date on the progress of your volunteering
- participate in annual volunteering reviews.

## Reviews

Reviews are set times to support the ongoing process of having open and honest conversations, giving and receiving feedback and an opportunity for us to thank you for your contribution to our work. Volunteering reviews are an opportunity to:

- discuss your role as a volunteer with the Trust
- receive feedback on your role and your opportunity to give feedback on the Trust to help us improve our performance
- discuss volunteering in the future
- discuss any support needs you may have.



You will have an initial review within six months of becoming a volunteer with the Trust. You will then be asked to participate in annual volunteering reviews once you have been with the Trust for over a year.

## Keeping up-to-date

The website is regularly updated and is an excellent way to keep up-to-date with the work of the Trust. On the website you'll find a section dedicated to supporting volunteers with information and resources, and also information on how to follow us on Facebook, Twitter, Instagram and LinkedIn. Please visit [www.msatrust.org.uk/get-involved/volunteer](http://www.msatrust.org.uk/get-involved/volunteer) for further information.

As a volunteer you can expect to receive:

- our magazine, MSA News, three times a year by email
- a volunteering e-newsletter, three times a year
- access to our Annual Review

## Providing feedback

We welcome all feedback as it helps us to improve what we do.

Please email [support@msatrust.org.uk](mailto:support@msatrust.org.uk) or call 0333 323 4591 (Mon-Fri 9.00am to 5.00pm). You can also write to:

Multiple System Atrophy Trust, 51 St Olav's Court, Lower Road, London SE16 2XB

## Claiming expenses

We are very grateful to many volunteers that meet incidental expenses with their own resources.

All volunteers are, however, entitled to claim reimbursement of all necessary and reasonable pre-agreed expenses incurred.

Please record mileages, keep all appropriate receipts, and submit your expenses on a Volunteer Expenses Claim Form within two months of these being incurred. To find out more about this please see our Volunteer Expenses Policy (a copy will be given to you at your induction) or look on the Trust website.

## Ending volunteering

You can, of course, stop volunteering whenever you wish but we ask that, wherever possible, you inform us in good time so that we can make alternative arrangements. If you are going away for extended periods or holidays, please just let us know.

## Can I get a reference?

Whilst we do not commit to providing references, where appropriate we can provide a written reference after you have been volunteering with us for one year. In these circumstances the reference given will be in writing, on Multiple System Atrophy Trust headed paper, and will contain information about the dates you were actively volunteering with us and a brief overview of the role undertaken.

# Health and safety

We have a responsibility to ensure the health, safety and welfare of our volunteers and we will ensure that we fully explain any health and safety risks associated with your role. We will provide information, instruction, supervision and training to enable you to work safely while volunteering with us.

As a volunteer we ask you to:

- take reasonable care of yourself and others
- follow the Health and Safety policy and procedures of the Trust
- report on any health and safety concerns you may have
- if you are office based then please inform our first aider of any allergies or additional needs you may have.

## Accidents/incidents and emergency situations

In the event of an emergency you should call 999 and alert the relevant emergency services.

You should also please contact our offices to notify us of the accident, incident or emergency. Our office number is **0333 323 4591** and our opening hours are Monday to Friday 9.00am to 5.00pm. Outside of these hours please leave us a short message with your contact details and we will be back in touch with you as soon as we can.

## Planning activities and events

Where any activities or events are being planned on behalf of the Trust, even by a third party, they must be planned in line with Trust guidelines. There are many health and safety issues that may need to be considered, so if you are planning such an activity/event please ensure you talk to us. Please note that the MSA Trust cannot take any responsibility or liability for events organised on our behalf.

## Safety of locations and venues

As a volunteer working with us you have a 'duty of care' to ensure that any location selected by you for any Trust activity (e.g. meeting, social event, etc.) is adequate and safe for the activity being undertaken. This means checking:

- appropriate facilities are available with disabled access (sanitary, welfare and first aid provision)
- correct licenses are held
- staff provided at the venue are competent to carry out their tasks safely
- the venue is free from potential hazards (such as trailing cables)
- fire precautions are in place (fire-fighting and alarm systems, signage, lighting, adequate escape routes, assembly points, and smoking policy) and that all attending the venue are briefed on the arrangements
- insurance cover is in place.

Finally, you should ensure that an adequate health and safety assessment has been carried out. A health and safety form can be provided by the Trust office.

## Insurance

The Trust's liability insurance policies include the activities of volunteers and liability towards them. The Trust does not insure volunteers' personal possessions against loss or damage.

## Motor insurance

Use of a personal vehicle for volunteering purposes is not automatically covered by standard car insurance. Whilst some insurance companies will count volunteering within the 'domestic, social and pleasure' category, others require it to be classified under business miles. The Trust recommends that anyone considering using their vehicle in connection with volunteer work should check the position with their motor insurer.

## Personal Safety

We want all volunteers to take all reasonable steps to ensure that their own personal safety is not put at risk. Please report all near misses, incidents, accidents and any concerns about personal safety that you identify or become aware of in the course of your volunteering. We ask that volunteers understand the boundaries of their role, for example not conducting home visits, and keeping within these. If you have any questions about what is acceptable within your role please contact the Trust office.

## Fire

If you start volunteering in an office you will be given guidance on fire safety, and the emergency procedures to follow in the event of an evacuation of the building. Information given will include:

- when the fire alarms are tested, and what they sound like;
- location of fire exits;
- where people should go on exiting the building
- whether there are any nominated Fire Marshals.

## First Aid

If you start volunteering in an office you will be given guidance on the first aid facilities and cover arrangements. We will inform you of any trained first aiders and the location details of first aid kits or rooms.

## Smoking

Smoke free laws have been introduced across the UK to protect employees and the public from the harmful effects of second-hand smoke. All premises and vehicles used on Trust business must therefore be smoke free.

## Further information

For copies of current policies relevant to volunteering and the most up-to-date advice and guidance, please contact us.

Last Updated: November 2018