



Multiple System Atrophy Trust

Volunteering Handbook

Version 1, November 2025

Multiple System Atrophy Trust. Registered Charity Number 1137652 (England & Wales) and SC044535 (Scotland).
128B Business Design Centre, 52 Upper Street, London, N1 0QH

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Contact Details

0333 323 4591

volunteer@msatrust.org.uk

Welcome to Volunteering at the MSA Trust

Volunteering is an immensely valuable gift that ensures people affected by multiple system atrophy (MSA) receive the support they need. We're grateful that you've chosen to give your time and skills to support our cause.

Volunteers are vital to our work. From Trustees to Support Group Helpers, Information Reviewers to Event Supporters, every volunteer plays an important role in supporting our vision of a World Free of MSA.

The aim of this handbook is to give you information about the Multiple System Atrophy Trust (MSA Trust), tell you how we will support you, and explain our volunteer policies and processes. We want it to be useful and helpful, so please give us your feedback on anything you think we could change.

Thank you for joining our volunteer team, from everyone at the MSA Trust.

“Volunteers are not paid – not because they are worthless, but because they are priceless”

About the MSA Trust

The MSA Trust is the UK and the Republic of Ireland's leading charity supporting people affected by MSA, a rare neurological disease with no known cause or cure. We fund research into MSA and support those affected by the condition.

We provide our MSA Community with access to:

- An MSA Health Care Specialist email and telephone support service.
- MSA-specific factsheets and information materials on a variety of topics, all easily accessible on our website.
- Regional online and in-person MSA Support Groups throughout the UK and Ireland.
- A Social Welfare Specialist Service which can give support with financial needs, care support, equipment and grants.
- A dedicated online MSA community on the HealthUnlocked Forum.
- Support and funding for voice banking.
- Webinars on a range of topics.
- MSA education and training sessions for health and social care professionals, led by our MSA Health Care Specialists.
- MSA Health Care Specialist attendance at specialist clinics around the UK.
- Special events such as MSA Candlelight and the Summer Social at Sarah's Wood.

We are also the principal funder in the UK of innovative and ground-breaking research into MSA. To date, over £2 million has been spent by the Trust on research grants focused on MSA.

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

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

You can read more at www.msatrust.org.uk/about-us/who-we-are/

MSA Trust Volunteer Agreement

This agreement explains what our volunteers can expect from the MSA Trust. It also explains what we ask of volunteers.

What you can expect from us:

- A named Role Manager to support you.
- To be treated with dignity, fairness and respect, in line with our policies.
- To be part of a friendly team of staff and volunteers.
- Induction and training appropriate to your role.
- A clear role description.
- Pre-agreed expenses.
- Experience in supporting people affected by MSA.
- Ongoing communications and updates.
- Appropriate measures so you can carry out your role safely (health and safety procedures, liability insurance).
- For any concerns or complaints to be managed in a professional, timely way, according to our policy.
- To be notified about any changes to roles or expectations, and included in discussions about changes whenever possible.

What we expect from you:

- To keep people with MSA at the heart of what we do.
- To carry out your role, as outlined in the role description, to the best of your ability.
- To keep in contact with your Role Manager and let them know of any updates, problems or worries you have about your role.
- Give as much notice as possible if can't make an event, meeting or deadline.
- Follow the Trust's volunteer policies and procedures.
- Follow health and safety guidance and speak to your manager if you have any questions or concerns.
- To report any health, safety and safeguarding concerns to the appropriate staff member.
- While carrying out your role, to treat everyone you encounter equally and with respect.
- Follow the confidentiality rules in the volunteer handbook and additional guidance relevant to your role.
- To respect the privacy of our MSA Trust Community and other volunteers, and not disclose information except in an emergency or if there are safeguarding concerns.
- Let your Role Manager know if you decide to leave your role, trying to give as much notice as possible.
- To not bring the charity into disrepute through your behaviour or actions.
- To not discriminate against any MSA Trust Community members, staff or fellow volunteers.

Support for You

When you start volunteering with us, we will put you in contact with a named Role Manager. This is a member of staff who is there to guide you through your role, answer questions during office hours, and give you support. You can contact them by email or phone.

The Trust also has a Volunteer Officer. They make sure the Trust's volunteering policies and processes are in line with best practice and oversee volunteering in the charity. They are also there to give you support in addition to your Role Manager. You can email them with any questions about volunteering, or reach out to them if you need support or to talk over any issues.

The Volunteer Officer emails a newsletter to all volunteers at least three times a year. This includes volunteering updates, information on new volunteering opportunities and news about the charity. We also email our magazine, MSA News, to all our volunteers.

Our volunteers sometimes ask if we can provide a reference for them. You need to have volunteered with us for at least a year, on a regular basis, before we can provide a written reference. We manage reference requests on a case-by-case basis. You can talk to your Role Manager or the Volunteer Officer if you want to ask for a reference.

Training and Development

When you start volunteering with us, we will tell you about any training that's needed. We want to make sure you have all the knowledge you need to carry out your role both well and safely. Your Role Manager or the Volunteer Officer will give you all the details you need.

Different roles involve different levels of training. If you're working directly with our service users, you might be asked to do some training around safeguarding, confidentiality or data protection.

If you feel you need additional training at any time, talk to your Role Manager or the Volunteer Officer. They might be able to offer 1-to-1 skills development sessions or access to some online or in-person training.

Diversity, Equity and Inclusion

The MSA Trust aims to treat all volunteers with fairness and equity. We believe everyone should be able to make a difference through volunteering, whatever their background. Our organisational culture is one of respect and inclusivity.

We will not discriminate against our volunteers and we will protect them from harassment and discrimination.

As a volunteer for the MSA Trust, we also ask you to treat the people you encounter while volunteering with fairness and respect. That includes service users, staff, fellow volunteers, or the wider public.

As a charity that delivers services, the MSA Trust must uphold the Equality Act and

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avoid unlawful discrimination. Volunteers must not discriminate against anyone who uses or is part of the service, including other volunteers and paid staff.

You must not discriminate against an individual in relation to, or because of, their age, disability, gender reassignment, marital or civil partner status, pregnancy or maternity, race, colour, nationality, ethnic or national origin, religion or belief, sex, or sexual orientation.

We welcome your feedback on how we might improve and make our volunteering more inclusive. You can ask for a copy of our Diversity, Equity and Inclusion policy and ask us questions about it or give us feedback.

Claiming Expenses

You should not be out of pocket due to your volunteering. We want to make sure nobody is excluded from volunteering because of their financial circumstances.

You can claim back the cost of travel related to your volunteering. If you are volunteering for over four hours a day, you might be entitled to a lunch or dinner allowance. Eligible expenses are listed in the Volunteer Expenses Policy, which you can find at the end of this handbook.

Before you incur expenses, you should talk to your Role Manager or the Volunteer Officer, so that you're both clear on what you can claim for. You should also talk to them if you can't cover a travel cost yourself (e.g. a train ticket to volunteer at an event) as we may be able to help with an advance payment or pay on your behalf.

Always remember to keep receipts and a record of any car mileage. There's a copy of the Volunteer Expenses Claim Form at the end of this handbook. You can ask your Role Manager or the Volunteer Officer for an electronic or a paper copy of the claim form, and they can help you complete it.

You might not want to claim expenses. We are very grateful to volunteers who choose to donate their expenses, but this is not expected. It's very helpful if you can tell us about the expenses you incur as a volunteer, even if you don't want to claim them back, because this helps us to budget for volunteering and to apply for funding.

Health and Safety

Health and safety is everyone's responsibility. We have a duty of care to our volunteers and we will explain any risks associated with your role. We'll also make sure you have appropriate induction and training to keep you safe.

Different roles come with different levels of risk and different training needs. For example, someone reviewing documents at home will need much less health and safety training than someone volunteering at an in-person support group or an event.

We ask that you take reasonable care of yourself and of other people while you are volunteering. If you have any health and safety concerns or you become aware of any risks you must let us know as soon as possible.

If you have any particular needs that we should be aware of (e.g. an allergy) then

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please let us know and we will work together to minimise any risks.

Insurance

You are covered by the Trust's public liability insurance while you're carrying out your designated volunteer role. Your personal possessions aren't covered by this insurance, so please take care of them while you're volunteering at a meeting or event where they could be at risk of loss or damage.

Car Insurance

If you're using your own vehicle to drive to and from your place of volunteering (e.g. an in-person support group meeting venue) you don't need to disclose this to your insurer. This doesn't count as 'volunteering activity' (just like driving to work isn't driving for business or commercial purposes).

If you think you need to use your vehicle as part of your volunteering role, you should talk to your Role Manager or the Volunteer Officer first to clarify. Then you need to tell your insurers. Explain you will only receive out-of-pocket expenses, to make it clear that this is not commercial use of the vehicle.

You shouldn't give a lift to anyone else (e.g. a support group or event attendee) without first speaking to your Role Manager for guidance.

Most insurance companies will count volunteering under 'domestic, social and pleasure' use and there won't be any cost impact, but some may require it to be classified under business miles. The Volunteer Officer can give you extra advice and guidance.

Personal Safety

Your personal safety is very important. None of our volunteer roles involve home visits or meeting up with service users outside of support groups or events.

If your role might involve occasional lone working (e.g. setting up a meeting room for an in-person support group, travelling to an event), your Role Manager will talk to you about keeping yourself safe. This could be as simple as contacting someone at the start or end of a journey, and having a charged mobile phone to hand with your Role Manager's number.

We also ask you take responsibility for your own safety, and to not put yourself at risk while volunteering. If you experience any incidents or accidents, or have any concerns about your personal safety, please report them to us as soon as possible.

Safeguarding

All staff and volunteers at the MSA Trust have a duty of care to keep people safe as far as possible.

As a volunteer with the MSA Trust you might encounter people at risk of abuse (also known as vulnerable adults). You may see or hear something that makes you concerned that a person is being abused. Abuse can include emotional, physical, sexual or financial abuse or neglect.

If you are worried about someone then make a factual record of the details given to you or what you observed. Then contact the Safeguarding Lead at the MSA Trust as soon as

possible (**within 48 hours**) and share your record with them. They will decide on what action is needed to keep someone safe.

If a vulnerable adult is in immediate danger, you must call the emergency services. Then make a report to the Safeguarding Lead as soon as you can.

You should never carry out your own investigations or confront anyone about your suspicions. It's important to keep yourself safe and to make sure the person at risk gets the right support and help.

The MSA Trust will provide additional safeguarding training if your role requires it. If you have any worries or concerns about safeguarding and what to do, please talk to the Volunteer Officer. Remember that staff are always available to support and help you if you have a safeguarding concern.

SAFEGUARDING LEAD: Andy Barrick andy.barrick@msatrust.org.uk

Confidentiality

While you're volunteering, people may share information about themselves (for example, during a chat at a support group or event). It is important that our service users know they can speak in confidence and that information is treated with respect. You shouldn't discuss or share these conversations with anyone outside of the MSA Trust.

The exception is when there is a safeguarding concern, when you need to share information because of a concern for someone's safety. Then you must follow the safeguarding procedure.

There may be times when you have the personal contact details of MSA Trust staff (for example a personal mobile number when working at an event). You should keep this information safe, not share it with anyone else, and delete it as soon as possible.

Data protection

Everyone has rights regarding how their personal information is handled. The MSA Trust collects, stores and processes personal information about service users and volunteers. Data is classed as any information stored in either in electronic or paper form, and personal information includes things that could identify a person (such as their name, address, date of birth).

Anybody has the right to request any information held on them and the Trust will process any requests as necessary according to the Data Protection Act 1998 and the General Data Protection Regulations (GDPR).

Our Privacy Notice details how we will handle information about you while you volunteer with us. We process personal information for volunteers including contact details, references or information needed to complete a DBS check. Your information is stored securely in our CRM system (Raiser's Edge) and on our shared drive (currently SharePoint/OneDrive).

We only keep your data for as long as we need it for, which will be at least for the duration of your volunteering with us, though in some cases we will keep your data for a period of 7 years after your volunteering has ended. You can read the full Privacy Notice on our website at www.msatrust.org.uk/privacy-notice/.

As a volunteer, you may be responsible for collecting a minimal amount of personal information. This information should only be collected as needed for a specific purpose (e.g. a register of names at an event or support group). Key points for protecting data are:

- Personal information should not be kept for longer than necessary and needs to be destroyed as soon as it's not needed (e.g. at the end of an event).
- Paper copies of personal information should be shredded.
- Electronic data (emails, phone notes) should be deleted when no longer needed.
- Any electronic information needs to be kept on a secure computer in a password-protected document.
- Any data sent over email needs to be password protected.
- All paper information should be stored in a locked cabinet.
- If your role involves speaking to MSA Trust Community members, none of their personal information should be shared without prior consent.
- Limit any personal information you carry while travelling to minimise risk of loss.

We can provide a copy of our data protection policy on request.

Your Role Manager and the Volunteer Officer are here to help and advise you. If you have any questions about collecting or holding personal information, please talk to them and they can tell you what to do.

You should report any data protection related incidents to a staff member in the Trust office as soon as possible, so they can be dealt with swiftly.

Concerns or Problems

We want you to enjoy volunteering with us and to feel safe and supported. However, if you have an issue or are unhappy with something related to your role, it's important that you know what to do. The full Volunteer Problem Solving document is provided in an appendix to this handbook.

Your Volunteer Role Description tells you what is expected of you and what you can expect from the MSA Trust. The Volunteer Agreement sets out the standard of behaviour expected of all volunteers. It's helpful to read through these documents if you have a problem or are worried about something to do with your volunteering.

If you are unhappy about something to do with your volunteer role, the first thing to do is speak to your named Role Manager. If they aren't available, or your concern involves your Role Manager, you can speak to the Volunteer Officer.

Explain what your concern is. They will listen and explain what they can do. Often, this informal conversation will be enough to solve any problems. Sometimes, staff might need to look into your concern and get more information. In this case they will tell you what they will do and give you a time they will respond by (where possible).

Taking Time Out

There might be a time when you need to take some time out from volunteering, because of health issues, a change in family circumstances, work, etc. If you need a break from volunteering, let your Role Manager or the Volunteer Officer know. They can make sure you get the support you need while you're on a break and keep in contact for when you're ready to start again.

Sometimes your Role Manager or the Volunteer Officer might suggest you take a break from volunteering, perhaps if you're going through a difficult time. This is to ensure you and anyone you are supporting (family or the people you support through volunteering) are kept safe and looked after appropriately.

Stopping Volunteering

We understand that things change, and there may come a time when you're not able to volunteer with us anymore. Where possible, it's good for us to have some notice that you'd like to stop volunteering, so that we can recruit someone to take on the role and make sure you have a positive end to your volunteer experience.

You can talk to your Role Manager or the Volunteer Officer, to let them know you're leaving. They will ask you about why you're leaving. This is to make sure you're not stopping volunteering because of any concerns or worries about your role. They might also ask you for some feedback; this is so we can make sure we keep improving the volunteering experience for the future.

If you have any equipment or materials related to your role that need to be returned, your Role Manager will arrange this with you.

Key Contacts

Your Role Manager:

Volunteer Officer: Kirsten Olufsen volunteer@mastrust.org.uk

MSA Trust main phone number: 0333 323 4591

Safeguarding Lead: Andy Barrick andy.barrick@msatrust.org.uk

APPENDIX

Expenses Policy

Expenses Form

Problem Solving Policy

MSA Trust Policy and Procedure: Volunteer Expenses

Why We Have This Policy

Volunteers should not be out of pocket due to their volunteering. The MSA Trust wants to make sure nobody is excluded from volunteering because of their financial circumstances.

This policy explains what expenses you can claim for and how to claim them.

Before Making a Claim

Volunteers should talk to their Role Manager or the Volunteer Officer before spending money on expenses, so that both are clear on what the volunteer is claiming for.

Before making a claim volunteers should check that:

- The expenses are necessary and incurred only while undertaking their role with the Trust.
- The expenses are reasonable and the most cost-effective method available was used.
- Spending was agreed in advance.
- Expenses were incurred within the last two months.

Always remember to keep receipts and a record of any car mileage.

Advance Claims

If a volunteer can't cover a travel cost themselves (e.g. a train ticket to volunteer at an event) they should speak to their Role Manager. The Trust may be able to help with an advance payment or pay on the volunteer's behalf.

Eligible Expenses

Volunteers can claim back the cost of travel related to their volunteering.

If they are working over four hours a day volunteering, they might be entitled to a lunch or dinner allowance.

Public Transport

Standard-class public transport should be used when travelling on behalf of the Trust. Volunteers should book tickets as far in advance as possible to make best use of any concessions, special offers or discounts. This includes bus, coach, train, tram, ferry and, where appropriate, air travel.

Tickets purchased should be for journeys made on behalf of the MSA Trust only.

If volunteers use a pre-pay scheme such as Oystercard, they must submit a print-out of the individual journeys made, highlighting which journeys are being claimed for.

The trust **cannot** cover the cost of any form of season ticket or railcard (such as senior or disabled person's railcards). These can be used for other journeys, so they are classed as a taxable benefit by HMRC.

Taxis

Taxis should only be used where they are essential for accessibility, where public transport is not practical, accessible, safe, or where there is an emergency.

Private Vehicles

If public transport is impractical or more expensive than the cost of the volunteer using their own vehicle, the Trust will reimburse travel at the following mileage rates:

The first 10,000 miles in the tax year	Over 10,000 miles in the tax year
Car 45p per mile	Car 25p per mile
Motorcycle 24p per mile	Motorcycle 24p per mile

These rates are set by HMRC and reviewed annually. Any changes following the annual HMRC review are at the Trust's discretion.

Parking costs, toll and congestion charges can also be claimed for where unavoidable. The Trust will not cover the cost of parking fines, speeding tickets or any other penalties.

Volunteers using their own vehicle to drive to and from their place of volunteering don't need to disclose this to their insurer. In rare situations where a volunteer needs to use their own vehicle as part of their volunteering role, they must talk to their Role Manager or the Volunteer Officer first. If use of the vehicle is agreed, the volunteer must then tell their insurers, explaining they only receive out-of-pocket expenses, to make it clear that this is not commercial use of the vehicle.

Most insurance companies count volunteering under 'domestic, social and pleasure' use and there won't be any cost impact. Rarely, some may require it to be classified under business miles. The Volunteer Officer can give extra advice and guidance in this situation.

Lunch

Volunteers working over four hours a day volunteering for the Trust are entitled to a £5 lunch or dinner allowance each day. Receipts must be kept for all purchases and submitted as detailed below. At some events (e.g. Summer Social, Tree Planting) lunch is provided and volunteers are not entitled to any additional lunch allowance.

Other Expenses

There may be occasions when volunteers are eligible to make claims for other expenses, such as subsistence, overnight accommodation, administration costs etc. Volunteers must always discuss this with their Role Manager before making any payments.

Reimbursement of Expenses

To make a claim, volunteers must use the Trust's Volunteer Expenses Claim Form. The form can be provided by Role Managers or the Volunteer Officer. Staff can help with completing the form if needed.

The claim form must be submitted by email or post within two months of the expense being incurred. The form should be sent to the Role Manager or Volunteer Officer.

Expenses will be paid by direct bank transfer using the details provided on the claim form. We aim to pay expenses within 2 weeks of receiving the completed form.

“Donating” Expenses

Some volunteers might not want to claim expenses, seeing them as a donation to support the Trust and save funds. The MSA Trust is very grateful to volunteers who choose to donate their expenses, but this is not expected.

If a volunteer chooses not to claim, it is still very helpful if they can tell the Trust about the expenses incurred as a volunteer. This helps staff to budget for volunteering and to apply for funding.



Volunteer Expenses Claim Form

Instructions for Volunteers

Please explain the reason for the expense in Column 2 of the form on Page 2. This might be travel to a meeting, purchasing refreshments for a support group, lunch expenses.

If you are claiming for car mileage, enter the number of miles travelled that day. Mileage is reimbursed at 45p per mile. Multiply your number of miles travelled by 45p to give the amount to claim for your journey.

Enter the Total Amount at the bottom of the table.

Sign and date the form after the total (if sending electronically a typed signature is acceptable).

Return this form to volunteer@msatrust.org.uk with electronic copies of receipts. Alternatively, post the completed form and paper receipts to: MSA Trust, 128B Business Design Centre, 52 Upper Street, London N1 0QH

If you have any questions or need help to complete this form, please contact the Volunteer Officer or your Role Manager

Volunteer details	Bank details
Name:	Sort Code:
Address:	Account No:
	Name of bank:

Volunteer Completes					MSA Trust Completes
Date	Detail expense and reasons (e.g. travel to a support group)	Receipt Attached	Number of miles travelled	Amount	Cost Code
			TOTAL		

Volunteer Signature:

Date:

MSA Trust Role Manager Signature:

Date:

MSA Trust Policy and Procedure: Volunteer Problem Solving

Why We Have This Policy

We want you to enjoy volunteering with us, and to feel safe and supported. However, if you have an issue or are unhappy with something related to your role, it's important that you know what to do.

This document tells you what to do if you have a concern and what you can expect from us. It also covers what we will do if we have any concerns about your performance of your volunteer role.

Your Volunteer Role Description tells you what is expected of you and what you can expect from the MSA Trust. The Volunteer Agreement sets out the standard of behaviour expected of all volunteers. It's helpful to read through these documents if you have a problem or are worried about something to do with your volunteering.

What to Do if You Have a Concern or a Complaint

If you are unhappy about something to do with your volunteer role, the first thing to do is speak to your named Role Manager. If they aren't available, or your concern involves your Role Manager, you can speak to the Volunteer Officer.

You can contact them by email or phone. Explain what your concern is. They will listen and explain what they can do. Often, this informal conversation will be enough to solve any problems.

Sometimes, staff might need to look into your concern and get more information. In this case they will tell you what they will do and give you a time they will respond by (where possible).

If an informal conversation hasn't been enough to address your issue, then you can speak to the Volunteer Officer or a senior manager at the MSA Trust.

In rare circumstances, if you're not happy with the response you get, or if you feel that the matter is more serious, you can make a formal complaint in writing.

We will record and acknowledge formal complaints within five working days of receiving them. Where possible we will aim to investigate your complaint within 15 days. If this is not possible we will keep you updated.

You can email your complaint to volunteer@msatrust.org.uk or post it to:

Multiple System Atrophy Trust
128B Business Design Centre
52 Upper Street
London N1 0QH

What We Will Do if There's a Concern About Your Volunteering

Sometimes, there might be concerns about how someone is carrying out their volunteer role. If your Role Manager becomes aware of a concern, they will have an informal conversation with you.

They will explain what the problem is and the impact it has had. You can discuss ways you can tackle the issue together. Depending on the situation, we might:

- Go over your role, its boundaries, and what's expected of you.
- Identify the need for more support or training.
- Change your task or put more resources in place.
- Decide that a different role might suit you better.
- Decide that this role isn't right for you.

With your Role Manager, you will agree what changes are needed and what you will both do. You'll agree when and how to review progress.

If the Problem Continues

If the problem doesn't improve, your Role Manager or the Volunteer Officer will talk with you again to see what else can be done.

Serious Problems

If things don't improve with time, or in situations where there is a serious concern about a volunteer's behaviour, they may be asked to leave the organisation.

In this rare situation, the Volunteer Officer consult with the CEO, then arrange a meeting with you. This might be in-person, online or on the phone.

They will explain that you're being asked to leave and the reason why. They will give you this information in writing after the meeting.

Learning and improving

We will take every opportunity to learn from concerns and problems. We will review our volunteer roles, induction and training and the support we offer volunteers. We will ask volunteers for their feedback and insight.