

**MSA Trust Confidentiality Policy**

**What this Confidentiality Policy covers**

The MSA Trust is committed to protecting your personal information and being transparent about what information we hold, whether you are a person affected by MSA, a donor, volunteer, shopper or campaigner.

Developing a better understanding of our beneficiaries and supporters through their personal data allows us to provide more targeted services and to fundraise more effectively, which ultimately helps us move towards our vision of a World Free of MSA. This policy attempts to demonstrate openness is at the core of what we do.

The purpose of this policy is to give you a clear explanation about how the MSA Trust uses the personal information you provide to us and that we collect, whether online, via phone, email, in letters or in any other correspondence or from third parties. It should be read in conjunction with our GDPR Privacy Policy here - <https://www.msatrust.org.uk/policy-statements>.

We ensure that we use your information in accordance with all applicable UK laws concerning the protection of personal information and the fundraising code of practice. This policy explains:

* What information the MSA Trust may collect about you
* How we will use that information
* Whether we disclose your details to anyone else
* Your choices regarding the information you provide to us.

If you have any queries about this Confidentiality Policy please contact the Data Protection Lead at the MSA Trust128B Business Design Centre, 52 Upper Street, London N1 0QH, telephone us on 0333 323 4591 or email support@msatrust.org.uk.

**Who we are**

The MSA Trust supports people affected by MSA in the UK and Ireland as well as funding research to find the cause, and one day cure, for MSA. Our registered charity number is 1137652 (England and Wales) and SC044535 (Scotland).

We are data controllers under data protection rules.

**Where we collect information about you**

We collect information in the following ways:

*When you give it to us directly*

You may give us your information in order to register with us as a member, request our support, sign up for one of our events, volunteer, make a donation, purchase our products or for research purposes.

Sometimes when you support us your information is collected or processed by a third-party organisation working for us, but we ensure that any contracts we hold with third-parties have robust data protection practices in place.

*When you give it to us indirectly*

Your information may be shared with us by independent event organisers, for example the London Marathon or fundraising sites like JustGiving. These independent third parties will only do so when you have indicated that you wish to support the MSA Trust and with your consent. You should check their Privacy Policy when you provide your information to understand fully how they will process your data.

*When you give permission to other organisations to share, or it is available publicly*

We may combine information you provide with information available from external sources in order to gain a better understanding of our supporters, to improve our fundraising methods, products and services.

The information we get from other organisations may depend on your privacy settings or the responses you give, so you should regularly check them. This information comes from, or is given to, the following sources:

* *Third party organisations*

You may have provided permission for a company or other organisation to share your data with third parties, including charities. This could be when you buy a product or service, register for an online competition or sign up with a comparison site.

 The only situations where we ever provide details to a third-party, other than as above, is when agencies act on our behalf to provide services for us under contract. For example, sending out MSA News by post or completing MSA Needs Survey projects, through conducting surveys and analysing data from these. We have ensured these companies or agents also adhere to Data Protection legislation and that they securely delete these records once their work for us is completed.

* *Social media*

Depending on your settings or the privacy policies for social media and messaging services like Facebook, WhatsApp or Twitter, you might give us permission to access information from those accounts or services.

* *When we collect it as you use our website or other platforms*

Like most websites, we use “cookies”. Cookies mean that a website will remember you. They’re small text files that sites transfer to your computer (or phone or tablet). They can make interacting with a website faster and easier. There are more details in our cookie policy - <https://www.msatrust.org.uk/cookie-policy/>.

Wherever possible we use aggregated or anonymous information which does not identify individual visitors to our website.

We may also use information you provide on other platforms (such as our MSA HealthUnlocked forum) to direct message with support for example.

* *Tracking*

We may use tags to track and improve the user experience on our sites, quality of service and to monitor the effectiveness of campaigns and digital marketing activity.

We may use them to:

* See what website content is popular and how people are using the site as they allow us to track users movement through our website. This type of information is amalgamated so that we can build up a picture of how the site is performing.
* Make sure we offer you a consistent service. For example, if we are testing new website content or we want to run a survey, we may use tracking to remember what content you have seen or if you have already been asked to join the survey.

In addition, when we email you, we may place a tag (also known as ‘tracking pixel’) on the email we send out. These let us monitor performance of our email marketing activity.

**What personal data we collect and how we use it**

The type and quantity of information we collect and how we use it depends on why you are providing it.

*Legal basis*

In most instances we rely on obtaining your consent for our use of your personal information. This is the case, for example, where we seek to obtain your consent to receive email or phone contact so we can support you with information, support or fundraising information.

In certain instances, we collect and use your personal information by relying on the legitimate interest legal basis. This is because when you, for example, request to receive services or products from the MSA Trust, we have a legitimate organisational interest to use your personal information to respond to you and there is no overriding prejudice to you by using your personal information for this purpose. This would include where appropriate, and demonstrably in your interest, ensuring our MSA Trust Health and Care Specialists can share relevant personal sensitive data with each other from our database in order to support people affected by MSA.

This is also the case with certain personal non-sensitive data, for example, where we process your donations in support of the MSA Trust’s objectives, for our internal administrative purposes, and where we need to take steps to protect our network security or risk of fraud.

We also use anonymised or unidentifiable information about you and your interactions with the Trust to demonstrate our impact, need for support and gaps in service provision. This data does not identify you, but will be shared with the public, funders, politicians, service providers and any interested parties. We have a legitimate organisational interest to use information in this way and there is no overriding prejudice to you by using your information for this purpose.

When collecting health data related to Multiple System Atrophy, we will rely on the substantial public interest legal basis to process your health data. This allows us as a not-for-profit organisation to process your information in relation to ‘Support for individuals with a particular disability or medical condition’. We may also break confidentiality if required due to safeguarding concerns or if requested by the police.

But to reiterate, in most instances, we rely on obtaining your consent for our use of your personal information.

*Your choice*

It is always your choice as to whether you want to receive support from us, information about our work and how we raise funds and the ways you can get involved through volunteering, campaigning and financially, for instance through fundraising event and appeals. If you do not want us to use your personal information in these ways please indicate your preferences when we collect your data.

You may opt-out of our marketing communications at any time by clicking the ‘unsubscribe’ link at the end of our marketing emails, by sending us an “opt-out” email or by following the instructions we provide you in our correspondences.

You can do this or change any of your email, mail, or phone contact preferences at any time by contacting us at support@msatrust.org.uk or phone 0333 323 4591.

We will not use your personal information for marketing purposes if you have indicated that you do not wish to be contacted by us for such purposes. However, we will retain your details on a suppression list to help ensure that we do not continue to contact you.

*Support for people living with and affected by MSA*

We provide services to support people living with and affected by MSA and collect personal data to deliver these services. In the course of this service provision, you may choose to offer details of a personal nature, in particular about you or someone else’s health. Only authorised staff will have access to this personal sensitive information which is kept on our CRM database (please see above section on legal basis), and this will not be shared with any unauthorised staff without your express permission.

We do use your anonymised data to show the impact of our services to the general public, funders, politicians and service providers. This information would also be used to highlight gaps in service provision or good practice. This could mean that unidentifiable information about you, your care needs and support would be shared as case studies or in aggregated data.

**Keeping your personal information**

We keep your personal information only for as long as is necessary to fulfil the purposes for which we collected it, including for satisfying any legal, tax, accountancy, reporting and our legitimate interest requirements. For marketing purposes this may be until you withdraw your consent or object to further contact. However, we will retain your details on a suppression list to help ensure that we do not continue to contact you. To determine the appropriate retention period for personal information, we consider the amount, nature and sensitivity of the personal information: the potential risk of harm from its unauthorised use or disclosure; the purpose for which we process it and whether we can achieve these purposes through other means; and the applicable legal requirements.

If you would like more information about the retention periods we apply to different aspects of your personal data, please contact us.

In some circumstances you can ask us to delete your personal information.

We may anonymise your personal information (so that it can no longer be associated with you) for research or statistical purposes in which case we may use this anonymous information indefinitely without further notice to you.

**Your right to know what we know about you, make a change or ask us to stop using your personal data**

You have the right to ask us to stop processing your personal data, and if it’s not necessary for the purposes you provided it to us for (e.g., processing your donation or registering you for an event) we will do so. Contact us on 0333 323 4591 or support@msatrust.org.uk if you have any concerns.

You have the right to ask for a copy of the information we hold about you. If there are any discrepancies in the information we provide, please let us know and we will correct them.

If you want access to your information, please use our subject access request form on our website <https://www.msatrust.org.uk/policy-statements/> or send a description of the information you want to see and proof of your identity by post to Data Protection Lead, MSA Trust, 128B Business Design Centre, 52 Upper Street, London N1 0QH.

If you have any complaints about the way in which we have used your personal information, please get in touch with us. We will be happy to discuss your concerns. In addition, you are also entitled to make a complaint to the Information Commissioner’s Office or to the Fundraising Regulator.

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2ndReview Jul23

Next review Jan25