



Privacy Policy (ADSHG_PP_v1-10-25)

Context and Scope

The ADSHG complies with UK data protection legislation, including the **UK GDPR, Data Protection Act 2018**, and the **Data (Use and Access) Act 2025**

We respect your privacy and are committed to protecting your personal data. In this policy we provide you with information on how we collect, store and use your personal information. We also tell you about your privacy rights and how the law protects you.

This policy applies to all staff, volunteers, and anyone working on behalf ADSHG, regardless of Clearly outline how ADSHG collects, stores, and uses personal data in accordance with data protection laws.

- Provide staff, volunteers, and associates with guiding principles for data protection.
- Ensure transparency and accountability in how personal information is handled.

Definitions

Personal Data: Any information relating to an identified or identifiable individual, including names, contact details, health information, and other sensitive data.

Policy Statement

The ADSHG is committed to upholding the rights and dignity of all individuals.

- We ensure compliance with data protection laws and promote transparency in our data handling practices.
- We provide appropriate guidance and support to staff and volunteers to ensure responsible data management.

Who we are

The Addison's Disease Self-Help Group (ADSHG) is a small rare disease charity and Patient Support Group registered in England and Wales with charity no. 1179825.

We are an **information controller** responsible for your data, and as such, are registered with the ICO (Information Commissioners Office).



What data we collect about you

We may collect, use, store and transfer the following kinds of personal information about you:

- Identity data including name, address, email, phone number, date of birth, and gender
- Donation data including details of your donations and your eligibility for Gift Aid
- Shop data including details of online purchases and delivery information
- Membership data including details of your membership with ADSHG and the online forum
- Technical data including IP addresses, browser type, version and similar, and how you use our website, products and services
- Other information you may choose to share through your use of our online forum.
- We may also collect details of your link to adrenal insufficiency / Addison's disease, such as whether you are a patient, parent or partner of a person with AD, the type of adrenal insufficiency you have, and how long you have been diagnosed for. It is optional if you choose to share that information with us.

We may collect this personal information in a variety of ways, including through our membership form, through your voluntary use of our online forum, if you donate or purchase, if you sign up to an event, if you agree to fundraise for us, or through any feedback or other communication you may send us.

If you do not provide personal data

Providing your personal information to ADSHG is optional. However, some is necessary to create your membership, to provide you with access to our online forum, to process your donations or to manage any purchases from our online shop. If you choose not to provide this information, we may not be able to carry out such actions for you.

Why we collect your personal data and how we use it

We will only use your personal information when the law allows us to. Most commonly, we will use your personal information in the following circumstances:

- To perform the transaction or contract we are entering into with you
- In our legitimate interests where your fundamental rights do not override those interests
- Where we need to comply with a legal obligation



Generally, we do not rely on consent as a legal basis for processing your personal information although we will get your consent before collecting any sensitive personal information, such as health-related data. In line with the 2025 updates to '**Soft Opt-In for Charities**', we may contact new supporters via email, SMS, or social media under the soft opt-in exemption, provided:

- The individual has shown interest or provided support.
- Communications relate to our charitable mission.
- Opt-out options are clearly provided at the point of data collection and in every message.
- You have the right to withdraw consent to marketing or our newsletters at any time by contacting us or using the 'unsubscribe' link in any of our email newsletters.

The ways we may use your personal information are:

- To register you and process your membership
- To ensure that your donations are properly processed and administer Gift Aid claims
- To send you our thanks or congratulations for a donation or fundraising
- To process any purchases from our online shop, via Shopify and a third-party fulfilment provider (Thrive Fulfilment)
- To provide you with access to our online forum and other online benefits
- To send you our newsletters if you subscribe to them
- To administer and protect the charity as necessary in our legitimate interest
- If necessary to comply with a legal obligation

In all cases, we will have a legitimate interest and, in some cases, a legal obligation in processing your personal information to maintain accurate and up-to-date records and monitor and consider our performance in relation to our charitable objectives.

Recognised Legitimate Interests: We may process personal data under recognised legitimate interests, such as fraud prevention, IT security, and public health, without requiring a Legitimate Interests Assessment.

Who has access to your personal information?

Your information may be accessed by employees or volunteers at ADSHG where necessary to process your information in accordance with this privacy policy.



We may share your information with suppliers who provide us with IT, system administration, data storage, marketing, payment processing, Gift Aid, donations processing, book keeping, accounting, newsletter printing, postage, packaging and fulfilment services.

We require all of these parties to respect the security of your personal information and to treat it in accordance with the law. We do not allow suppliers to use your information for other purposes and only permit them to process it in accordance with our instructions.

Security of your personal information

We take the security of your personal information seriously, and we have put in place appropriate security measures, internal policies and controls to prevent your information from being lost, corrupted, stolen, or accessed in an unauthorised way. In addition, we limit access to your personal information to those employees, volunteers and other third parties who have a need for it. They will only process your personal information on our instructions and are subject to a duty of confidentiality.

We have put in place procedures to deal with any data breach and will notify you and any applicable supervisory authority of a breach where we are legally required to do so.

By preference we choose suppliers who are based in the UK and keep our data in the UK. Where we are required to work with a supplier outside the UK and EEA, processing of your personal information may involve an international transfer. Whenever we transfer your personal information out of the UK or EEA, we ensure a similar degree of protection is afforded to it by ensuring that adequate safeguards are implemented such as requiring our suppliers to enter specific contracts which give personal data the same protection it has in the UK and EEA.

For how long do we keep your personal information?

We will only retain your personal information for as long as reasonably necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, regulatory, tax, accounting or reporting requirements.

We may retain your personal information for a longer period in the event of a complaint or if we reasonably believe there is a prospect of litigation in respect to our relationship with you.

To determine the appropriate retention period for personal information, we consider the amount, nature and sensitivity of the information, the potential risk of harm from unauthorised use or disclosure of your information, the purposes for which we process



your information and whether we can achieve those purposes through other means, and the applicable legal, regulatory, tax, accounting or other requirements.

Cookie Consent

We use cookies for analytics, site optimisation, and functionality. Consent is not required for these categories, but users can manage preferences via browser settings.

Changes to this privacy policy and your duty to inform us of changes

We keep our privacy policy under regular review. It is also important that the personal information we hold about you is accurate and current in order for us to continue to effectively provide you with membership or other services; please keep us informed if your personal information changes during your relationship with us.

Your legal rights

Under certain circumstances, you have rights under data protection laws in relation to your personal information – this is known as a Subject Access Request (SAR).

This allows you to ask us:

- **What personal data** we hold about you.
- **Why** we are processing it.
- **Where** we got the data from.
- **Who** we've shared it with.
- **How long** we'll keep it.
- **Your rights** under data protection law (e.g. correction, deletion). You may request corrections to information that we hold about you (NB we may need to verify any new information you provide to us), or request deletion of your personal information where there is no good reason for us continuing to process it (NB we may not always be able to comply, for legal reasons)

You may:

- Object to processing of your personal information where we are relying on a legitimate interest and you feel it impacts on your fundamental rights and freedoms



- Withdraw consent at any time where we are relying on consent to process your personal information
- Request the transfer of your personal information to you or to a third party

Please contact us at operationsmanager@addisons.org.uk if you would like to exercise any of these rights. We will respond to SARs with a reasonable and proportionate search, balancing transparency with operational feasibility as a small charity.

Note that we may need to confirm your identity before complying. If you believe that we have not complied with our data protection obligations you should ask to talk to a trustee in the first instance. If you are not satisfied with the response you can raise a formal complaint with us.

Roles and Responsibilities

- **Trustees:** Ensure the charity has effective data protection policies and procedures in place.
- **Director:** Oversee the implementation of this policy and act as the main point of contact for data protection concerns.
- **Staff and Volunteers:** Understand and comply with this policy, attend training, and report any concerns to the Director

Reporting and Responding to Concerns

If you have any questions about this privacy policy or our notices, including any questions on how you may exercise your privacy rights, please contact us at operationsmanager@addisons.org.uk

We maintain a formal complaints procedure for data protection concerns. Individuals are encouraged to contact us before escalating to the Information Commissioner's Office (ICO) www.ico.org.uk. We acknowledge the ICO's expanded powers under the DUAA and PECR, including the ability to issue fines up to £17.5 million or 4% of global turnover.

Training and Support

- All staff and volunteers will receive appropriate levels of training / information on data protection
- Regular updates and refresher training will be provided as appropriate to ensure ongoing awareness and understanding.

Safeguarding exceptions

The General Data Protection Regulation enables the lawful sharing of information. It does not prevent the sharing of sensitive and personal information between organisations where the public interest in protecting people outweighs the public interest served by protecting confidentiality.

Monitoring and Reviewing

This policy will be reviewed every 2 years by the Director, and any updates communicated to staff and volunteers.