



Addisons Disease Self-Help Group (ADSHG)

Data Protection Policy

Document Owner	Director / Data Protection Lead
Approved By	Board of Trustees
Version	1.0
Review Date	• Annually; • Following significant legislative change;

Purpose

The Addisons Disease Self-Help Group (ADSHG) is committed to protecting the privacy and personal information of our members, supporters, volunteers, customers and stakeholders.

This policy sets out how ADSHG complies with the UK General Data Protection Regulation (UK GDPR), the Data Protection Act 2018, the UK Data Act and relevant guidance issued by the Information Commissioner's Office (ICO). It applies to all employees, trustees, volunteers and contractors who process personal data on behalf of ADSHG.

Given the nature of our work, ADSHG processes health information relating to people living with Addison's disease and other adrenal conditions. This information is treated with particular care as it constitutes Special Category Data.

Scope

This policy applies to all personal data processed by ADSHG, including information collected through:

- Membership registrations
- Online community forums
- Surveys and research activities
- Event registrations
- Fundraising activities



- Website contact forms
- Online shop purchases
- Volunteer applications
- Email communications
- Social media interactions where personal information is provided

Data Protection Principles

ADSHG will ensure personal data is:

1. Processed lawfully, fairly and transparently.
2. Collected only for specified and legitimate purposes.
3. Adequate, relevant and limited to what is necessary.
4. Accurate and kept up to date.
5. Retained only as long as necessary.
6. Kept secure and protected from unauthorised access, loss or disclosure.
7. Processed in a manner that demonstrates accountability.

Types of Data We Process

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

Standard Personal Data

This may include:

- Name
- Postal address
- Email address
- Gender
- Date of Birth
- Job Title



- Organisation/Company
- Telephone number
- Membership details
- Donation history
- Event attendance records
- Purchase history

Special Category Data

Due to the nature of the organisation, ADSHG may process:

- Information about adrenal insufficiency, including Addison's disease
- Medication information voluntarily provided
- Information relating to emergency injection kits
- Survey responses regarding health conditions
- Information shared within member forums
- Other concurrent health conditions related to Addison's Disease or Adrenal Insufficiency.

Special Category Data will only be collected where there is a lawful basis and an appropriate condition for processing under UK GDPR.

Online Forum and Community Data

ADSHG operates an online member forum that requires registration.

Members should be aware that:

- Information voluntarily posted in discussion forums may reveal health-related information.
- Forum users are responsible for the information they choose to share.
- Forum moderators may review posts to ensure community safety and compliance with forum rules.
- Health information shared in the forum will not be used for marketing purposes.
- Members may request deletion of forum accounts where legally permissible.



The forum should not be used to share sensitive information about other individuals without their consent.

Surveys and Research

From time-to-time ADSHG may conduct surveys to understand member experiences and improve services.

When undertaking surveys:

- Participation will generally be voluntary.
- The purpose of the survey will be explained at the point of collection.
- Anonymous responses will be used wherever possible.
- Health-related responses will be restricted to authorised personnel.
- Survey results may be published in aggregated form so individuals cannot be identified.

Shop Purchases

ADSHG may sell products including emergency injection kits, training materials, medical accessories and related support resources.

When processing orders, ADSHG may collect:

- Name
- Delivery address
- Email address
- Order history
- Product selections

Purchase records may indirectly reveal medical conditions. For this reason, order information will be treated confidentially and access restricted to those who need it for order fulfilment, customer service or financial administration.

Payment card information will not be stored by ADSHG where payments are processed by a third-party payment provider.



Lawful Basis for Processing

We will only use your personal information when the law allows us to. ADSHG may process personal information under one or more of the following lawful bases:

- Consent
- Contract
- Legal obligation
- Legitimate interests
- Vital interests

Where health information is collected, ADSHG will identify an appropriate UK GDPR condition for processing Special Category Data before collection.

Data Sharing

ADSHG will not sell personal information.

Information may be shared with:

- Payment providers
- Website and hosting providers
- Email distribution providers
- Professional advisers
- Regulators where legally required

Any third-party supplier processing personal data on behalf of ADSHG must provide appropriate security assurances.

Data Security

ADSHG will take proportionate measures to protect personal information, including:

- Password-protected systems and accounts
- Multi-factor authentication where available
- Secure cloud storage
- Regular software updates
- Staff and volunteer awareness training



Because ADSHG is a small organisation, security controls will be proportionate to the volume and sensitivity of the data held.

Retention

Personal information will not be retained longer than necessary. 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.

As a guide:

Record Type	Retention Period
Membership records	Duration of membership plus 3 years
Forum accounts	Until closure plus 12 months
Survey responses	Up to 3 years unless anonymised
Shop transaction records	6 years for financial compliance
Trustee and governance records	6 years after cessation
Safeguarding or incident records	In accordance with safeguarding requirements

Where practical, data will be anonymised rather than retained in identifiable form.

Personal Data Breaches

Any actual or suspected data breach must be reported immediately to the Chief Executive or nominated Data Protection Lead.

ADSHG will:

1. Assess the nature and impact of the breach.
2. Take immediate steps to reduce harm.
3. Record the incident.
4. Notify the Information Commissioners Office (ICO) where legally required.
5. Inform affected individuals where there is a high risk to their rights and freedoms.



Individual Rights

Individuals have rights under UK GDPR, including:

- Right to be informed
- Right of access
- Right to rectification
- Right to erasure
- Right to restrict processing
- Right to data portability
- Right to object
- Rights relating to automated decision-making

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 opsmanager@addisons.org.uk. Requests should normally be responded to within one calendar month. Individuals are encouraged to contact us before escalating to the Information Commissioner's Office (ICO) www.ico.org.uk.

Direct Marketing

ADSHG will only send marketing and fundraising communications where there is an appropriate lawful basis. 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

Service-related communications regarding membership, orders or essential organisational updates may continue where necessary.



Responsibilities

Board of Trustees

The Board has overall responsibility for ensuring ADSHG meets its data protection obligations.

Director / Risk Finance and Investment Sub-Committee

Responsible for:

- Maintaining compliance
- Managing breaches
- Handling rights requests
- Ensuring policies remain current

Staff and Volunteers

Everyone handling personal information must:

- Follow this policy
- Keep information secure
- Report concerns promptly
- Only access information needed for their role

Policy Review

This policy will be reviewed annually or sooner where there are significant changes to legislation, organisational activities, systems or risks.