

1. Introduction

This Privacy Notice explains in detail the types of personal data we may collect about you when you interact with us. It also explains how we'll store and handle that data, and keep it safe.

We know that there's a lot of information here, but we want you to be fully informed about your rights, and how the Sleep Apnoea Trust uses your data.

We hope the following will answer any questions you have but if not, please do get in touch with us.

It's likely that we'll need to update this Privacy Notice from time to time. We'll notify you of any significant changes, but you are welcome to come back and check it whenever you wish.

2. What is The Sleep Apnoea Trust?

The Sleep Apnoea Trust Association, which we'll refer to as 'the Trust' in this document, is a UK charity registered on 29th June 1996 to promote the understanding and treatment of sleep apnoea in the UK.

3. Explaining the legal bases we rely on

The law on data protection sets out a number of different reasons for which a company may collect and process your personal data, including:

a) Consent

When you join the Trust we collect specific personal data and process your data with your consent.

The terms and conditions of membership, as explained in the joining email and welcome letter, clearly state that our primary communication with you will be by email. For those without email or not wishing to use email communication, you can opt in to use post as the primary communication. Members can choose to have both email and post if they wish.

The regular newsletter, Sleep Matters, has a separate choice, so a member using email can request Sleep Matters by post as well as or instead of email. If you have provided us with a mobile phone number, we may occasionally, contact you using a text message.

b) Contractual obligations

In one circumstance, we need your personal data to comply with our contractual obligations.

If you have registered with us for Gift Aid on membership contributions and donations, we are obliged by Her Majesty's Revenue and Customs (HMRC) to provide your title, first name, last name, first line of your address, postcode, the amount you paid us and when, for each fiscal year in which we have made one or more claims.

There are no other circumstances when we would provide personal data.

c) Legal compliance

If the law requires us to, we may need to collect and process your data, such as details of people involved in fraud or other criminal activity affecting the Trust.

d) Legitimate interest

In specific situations, we require your data to pursue our legitimate interests in a way which might reasonably be expected as part of running our charity and which does not materially impact your rights, freedom or interests.

For example, we will use your personal data when you book a place at the SATAday conference or any other conference or meeting we may organise.

Occasionally, we will email you an invitation to participate in some research and development being carried out by a third party. It is your decision to respond to the invitation and become involved and you decide how much of your personal detail you provide. NB We do not share any personal information whatsoever with that third party.

4. When do we collect your personal data?

When you joined the Sleep Apnoea Trust Association.

5. What sort of personal data do we collect?

a) From your membership application and medical alert card application: title, name, address, email, telephone numbers, sleep apnoea type, date of joining, how long on CPAP, Sleep Clinic attended, Gift Aid decision.

b) Also we collect notes of contacts with you, such as amendment to email address, registering for the SATAday conference and other details you wish to share with us.

c) Payment detail is kept for the 12 months following payment and deleted after the audited accounts of the fiscal year in which you paid are accepted at the Annual General Meeting in October/November, then deleted (see 8d for HMRC exception).

d) We do not keep payment card details when you pay us by phone.

6. How and why we use your personal data.

We use your data to manage your membership and to provide your membership benefits, e.g. Medical Alert card

Please be advised that if you choose not to share your personal data with us, or refuse certain contact permissions, we will not be able to continue to manage your membership, in which case your membership would end.

7. How we protect your personal data

We know how much data security matters to all our members. With this in mind we will treat your data with the utmost care and take all appropriate steps to protect it.

8. How long will we keep your personal data?

- a) As long as you are a member of the Trust.
- b) If your membership ends, we will keep records for 12 months following the cancellation for fiscal year auditing purposes and until the accounts for that fiscal year have been accepted by the AGM.
- c) At the end of that retention period, your data will either be deleted completely or anonymised, for example by aggregation with other data so that it can be used in a non-identifiable way for statistical analysis.
- d) In the case of Gift Aid, HMRC requires us to keep records for six years after a claim is made, irrespective of membership status. The information we collect is Title, First Name, Last Name, First Line of Address, Postcode, Amount Paid, and Date of Payment. Six years after the claim, the data will be deleted.

9. Who do we share your personal data with?

We do not share your personal information with any third party other than HMRC for Gift Aid Claim purposes, unless otherwise stated.

10. What are your rights over your personal data?

a) You have the right to request:

- i. Access to the personal data we hold about you, free of charge in most cases.
- ii. The correction of your personal data when incorrect, out of date or incomplete.
- iii. For example, when you withdraw consent, or object and we have no legitimate overriding interest, or once the purpose for which we hold the data has come to an end (such as the end of membership).
- iv. You have the right to request a copy of any information about you that the Trust holds at any time and also to have that information corrected if it is inaccurate. To ask for your information, please contact **Data Protection Officer, Sleep Apnoea Trust, PO Box 60, Chinnor, Oxon, OX39 4XE** or email info@sleep-apnoea-trust.org.
- v. To ask for your information to be amended, please contact the Managing Secretary by phone 0800 025 3500, email info@sleep-apnoea-trust.org or write to **Sleep Apnoea Trust, PO Box 60, Chinnor, Oxon, OX39 4XE**.
- vi. If we choose not to action your request we will explain to you the reasons for our refusal.

b) Your right to withdraw consent

When you join SATA, you have given us your consent to use your personal data, but you have the right to change your mind at any time and withdraw that consent. However if you do so your membership will end (see Section 6b)

c) Where we rely on our legitimate interest

In cases where we are processing your personal data on the basis of our legitimate interest, you can ask us to stop for reasons connected to your individual situation. We will then do so, but your membership will end.

d) Checking your identity

To protect the confidentiality of your information, we will ask you to verify your identity before proceeding with any request you make under this Privacy Notice. If you have authorised a third party to submit a request on your behalf, we will ask them to prove they have your permission to act.

11. Help Line Privacy Notice

At the Sleep Apnoea Trust Association (SATA) and the Scottish Association for Sleep Apnoea (SASA) we take your privacy seriously.

We will only use your personal information to assist us in our efforts to help you.

We only collect information that we need for specific purposes.

We keep all data secure while it is in our possession.

We ensure all data is relevant and kept up to date.

We will only hold as much data as we need and only for as long as we need it.

In exceptional cases and only if you provide us with written permission (or in an email), we will share your information with a third party for the specific purpose of obtaining progress in your enquiry.

Once your case is closed the data is securely destroyed.

12. Contacting the Regulator

If you feel that your data has not been handled correctly, or you are unhappy with our response to any requests you have made to us regarding the use of your personal data, you have the right to lodge a complaint with the Information Commissioner's Office. You can contact them by calling 0303 123 1113.

Or go online to www.ico.org.uk/concerns (opens in a new window; please note we can't be responsible for the content of external websites)

If you have any questions that haven't been covered, please contact our Data Protection Officer who will be pleased to help you:

- Email us at: info@sleep-apnoea-trust.org
- Or write to us at **Data Protection Officer, Sleep Apnoea Trust, PO Box 60, Chinnor, Oxon, OX39 4XE**.