

Privacy Notice

1. Who are we?

Lymphoedema Support NI is registered with the Charity Commission for Northern Ireland (NIC101768) and is recognised as a charity by the Inland Revenue under reference XR68639.

We aim to provide information and support for people suffering from lymphoedema in Northern Ireland, to work towards the availability of better resources for lymphoedema treatment and to work in partnership with local healthcare professionals and others involved in the statutory and voluntary sectors.

2. What is this notice?

In order to provide our Services, we may need to process **Personal Data** (that is information about someone who can be identified from the data). This Personal Data may be about you or other people. This notice explains how we will use the Personal Data we hold.

As part of our Services, we may transfer Personal Data to other people. At paragraph 7 below, we have set out a list of people to whom we might transfer Personal Data. This notice only deals with our use of Personal Data.

From time to time, we may need to change this privacy notice. If we do, we will let you know, so please do keep an eye on our privacy notice, which is on our website:

www.lymphoedemasupportni.org

All the defined terms in this notice are explained in paragraph 14 below. If you have any questions about this notice, feel free to send us an email to info@lymphoedemasupportni.org, or write to us at Lymphoedema Support NI, PO Box 851, Belfast, BT9 6WY.

3. About whom do we hold Personal Data?

We hold Personal data about the following groups of people (Data Subjects):

Data Subjects	Description
Members	that is any party, who has signed up to be a member of our organisation.
Supporters	that is any party, who or which have supported our work in any way, including those who have provided funding.
Beneficiaries	that is any individuals, who receive our services.
Website users	visitors to https://www.lymphoedemasupportni.org .

4. We are a **Controller** in respect of the Personal Data Subjects, as detailed above. This means we make decisions about what data to collect and how to use it.

5. From where do we collect Personal Data?

We collect Personal Data in the following ways:

Membership

Source	Types of Data Collected
Direct interactions with our members	Name and Contact Data, such as home address, email address, phone number. Transaction Data, such as membership subscriptions, donations. Membership Surveys.

Supporters

Source	Types of Data Collected
Direct interactions with supporters	Contact and Identity Data Transaction Data and Business Data.
Publicly available resources (internet, Companies House)	Contact and Identity Data Job Roles and Business Data.

Website Users

Source	Types of Data Collected
Our Website	Information about your use of our website and the device used to access it, for instance your IP address and geographical location. This information helps us to build a profile of our website users. We cannot identify you individually from this data.

It is likely that some of the Personal Data, which we collect, may include **Special Categories of Personal Data**.

We do not collect sensitive data about you unless there is a clear and valid need to do so within the law. For example, we may collect information about your condition to provide you with the support that you have asked for.

General

We may collect, use and share **Aggregated Data**, such as statistical, financial, or demographic data, which we collect from interactions with Data Subjects (on the basis that no individual can be identified from the data).

6. How will we use the Personal Data we hold and what is our lawful basis for doing so?

Members

- (i) We hold and process Personal Data as a Controller, which means we must have a 'lawful basis' for doing so. We have set out how we use Personal Data along with our lawful basis in the table below.
- (ii) Anywhere we are relying on legitimate interest, we believe that such processing is necessary for the purposes of our **legitimate interest**, which in this case is to function as a business.

We consider such use goes no further than the Data Subject would expect, is likely to align with the Data Subject's interests (by enabling us to provide a sustainable business model) and is unlikely to be detrimental to the fundamental rights and freedoms of the Data Subject.

Purpose/ Activity	Description	Types of Data	Lawful Basis	Condition for Special Categories
To provide our services		Identity Data Contact Data Transaction Data Health Information	Necessary for the performance of the contract for the provision of our services or taking steps necessary to enter into a contract.	Substantial public interest: support for individuals with a particular disability or medical condition (Data Protection Act 2018 Schedule 1 Paragraph 16).
To manage our relationship with you as a member		Identity Data Contact Data Transaction Data	Necessary for the performance of the contract for the provision of our services or taking steps necessary to enter into a contract. Legitimate Interest.	
Customer profiling and analysing members' preferences; Research, statistical analysis.	Members' questionnaires/ surveys	Members' opinions, medical experience, preferences.	Improving our services.	Substantial public interest: support for individuals with a particular disability or medical condition (Data Protection Act 2018 Schedule 1 Paragraph 16).
Administration and Dispute Resolution		Identity Data Contact Data Transaction Data	Legitimate Interest.	

7. Will we disclose the data to anyone else?

To claim Gift Aid on subscriptions and donations, we are required to collect declaration forms to verify your status as a UK taxpayer, which will include your name and home address. We retain these records, which HMRC may ask to see.

Data Subject Group	Types of Data Transferred	Recipient	Reason for Transfer
Members	Contact Data Transaction Data	Financial Services HMRC	Necessary for performance of the contract for the provision of our services or taking steps necessary to enter into a contract.
Supporters/Donors	Contact Data Transaction Data	Financial Services HMRC	Necessary for performance of the contract for the provision of our services or taking steps necessary to enter into a contract.

If you have any questions regarding to whom your data might be transferred, please send us an email at info@lymphoedemasupportni.org

8. What security measures do we have in place?

8.1 It is our policy to ensure that all Personal Data held by us is handled correctly and appropriately according to the nature of the information, the risk associated with mishandling the data, including the damage that could be caused to an individual as a result of loss, corruption and/or accidental disclosure of any such data, and in accordance with any applicable legal requirements.

8.2 We will use technical and organizational measures to safeguard your personal data, for example:

- we store your personal data on secure servers;
- payment details given through trusted industry-standard payment providers are encrypted, using SSL technology;
- USB devices, which are being carried around/used in other venues, are encrypted; hard files kept in a locked filing cabinet; burglar alarm in premises.

While we will use all reasonable efforts to safeguard your personal data, you acknowledge that the use of the internet is not entirely secure and for this reason we cannot guarantee the security or integrity of any personal data that is transferred from you or to you via the internet.

9. Where do we store the data we collect?

9.1 We only use servers in the European Union (EU). Our current host servers are provided by AVEC Solutions, whose servers are based in the EU.

10. What is our retention policy for client contact data?

10.1 **Our retention policies for Members and Supporters data are as follows:**

- (a) we may store data related to financial transactions for up to six years to ensure that we have sufficient records from an accounting and tax perspective;

- (b) we may archive data relating to negotiations, contracts agreed, payments made, disputes raised and your use of our software for up to six years to protect ourselves in the event of a dispute arising between you and us;
- (c) we may store aggregated data without limitation (on the basis that no individual can be identified from the data).

11. What rights do you have about the personal data we collect and hold?

11.1 You have the following rights in respect of Personal Data relating to them, which can be enforced against whoever is the **Controller (Lymphoedema Support NI)**.

- (a) **Right to be informed:** the right to be informed about what Personal Data the Controller (Lymphoedema Support NI) collects and stores about you and how it is used.
- (b) **Right of access:** the right to request a copy of the Personal Data held, as well as confirmation concerning:
 - (i) the purposes of the processing
 - (ii) the categories of personal data concerned
 - (iii) the recipients to whom the personal data has/will be disclosed
 - (iv) for how long it will be stored
 - (v) if data was not collected directly from the Data Subject, information about the source
- (c) **Right of rectification:** the right to require the Controller (Lymphoedema Support NI) to correct any Personal Data held about you, which is inaccurate or incomplete.
- (d) **Right to be forgotten:** in certain circumstances, the right to have the Personal Data held about you erased from the Controller's (Lymphoedema Support NI) records.
- (e) **Right to restriction of processing:** the right to request the Controller (Lymphoedema Support NI) to restrict the processing carried out in respect of Personal Data relating to you. You might want to do this, for instance, if you think the data held by the Controller is inaccurate and you would like to restrict processing the data until it has been reviewed and updated if necessary.
- (f) **Right of Portability:** the right to have the Personal Data held by the Controller (Lymphoedema Support NI) about you transferred to another organisation, to the extent it was provided in a structured, commonly-used and machine-readable format.
- (g) **Right to object to direct marketing:** the right to object where processing is carried out for direct marketing purposes (including profiling in connection with that purpose).
- (h) **Right to object to automated processing:** the right not to be subject to a decision based solely on automated processing (including profiling), which produces legal effects (or other similar significant effects) on you.

If you want to avail of any of these rights, you should contact us immediately at info@lymphoedemasupportni.org. If we are not the Controller, we will need to transfer your request to the Controller – but we will only do so with your consent. If you do contact us with a request, we will also need evidence that you are who you say you are to ensure compliance with data protection legislation.

12. What happens if you no longer want us to process Personal Data about you?

12.1 If we are holding Personal Data about you, as a Controller we will comply with your request unless we have reasons for lawfully retaining data about you.

12.2 If we are holding Personal Data about you and using that data for marketing purposes, or for any other activities based on your consent, you may notify us at any time that you no longer want us to process Personal Data about you for particular purposes, or for any purpose whatsoever, and we will stop processing your Personal Data for that purpose. This will not affect your ability to receive our Services.

13. Who do you complain to if you are not happy with how we process Personal Data about you?

13.1 If you have any questions or concerns about how we are using Personal Data about you, please contact our Data protection Officer immediately at our registered address (see paragraph 1.1 above), or by email to info@lymphoedemasupportni.org

13.2 If you wish to make a complaint about how we have handled Personal Data about you, you may lodge a complaint with the Information Commissioner's Office by following this link: <https://ico.org.uk/concerns>.

14. What do all of the defined terms in this privacy notice mean?

14.1 Throughout this notice, you will see a lot of defined terms (which you can recognise because they are capitalised). Where possible, we have tried to define them as we go, but we thought it might be useful to have a glossary at the end for you. Anywhere in this notice you see the following terms, they will have the following meanings:

Controller is a legal term set out in the General Data Protection Regulation (**GDPR**). It means the party responsible for deciding what Personal Data to collect and how to use it.

Data Subject means the individual, who can be identified from the Personal Data.

Personal Data means data, which can be used to identify a living individual. This could be a name and address, or it could be a number of details, which when taken together, make it possible to work out who the information is about. It also includes information about the identifiable individual.

Processor is another legal term set out in the GDPR. It means the party, who has agreed to process Personal Data on behalf of the Controller.

Special Categories of Personal Data means details about an individual's race or ethnicity, religious or philosophical beliefs, sex life, sexual orientation, political opinions, trade union membership, information about health and genetic and biometric data.

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