

CONFIDENTIALITY POLICY AND PROCEDURE

POLICY MONITORING	
Person responsible for Policy	Chief Executive
Committee responsible for Review	Board of Trustees
Policy approved	February 2023
Frequency of Review	3 years
Date of next Review	February 2026

1. Principles

Aim

- 1.1 Lymphoma Action aims to provide a confidential, high quality service that meets the needs of people affected by lymphoma (including carers, partners, family and friends) and other service users, and is respected by professional bodies and credible to the wider public.
- 1.2 Central to this aim is the development of trusting relationships, founded on confidentiality, between people affected by lymphoma and other service users, Trustees, staff members, volunteers and other contacts. We also recognise that our data protection policy and procedures are central to the building of trust and maintenance of confidentiality.

Children and adults

- 1.3 It is accepted that children warrant the same duty of confidentiality as adults.

Communicating and publicising the policy

- 1.4 Lymphoma Action's Confidentiality Policy and Procedure and the principles upon which it is based, will be communicated to those people affected by lymphoma, or other service users with whom staff or representatives work or engage directly. All Trustees, staff members, trainers, and volunteers, will sign a Confidentiality Agreement upon commencing employment or taking on a role (a copy of this agreement is included in the appendix to this document). Anyone else working for or on behalf of the charity, either directly or indirectly, paid or unpaid (on as an external contractor) should be asked to sign a Confidentiality Agreement where it is deemed necessary or appropriate by the Chief Executive or a member of the Senior Management Team. The fact that we have a Confidentiality Policy and Procedure in place is mentioned in appropriate promotional literature, our publications, on our website and in other relevant material.

Training

- 1.5 Lymphoma Action staff and volunteers will be trained on the Confidentiality Policy and Procedure as part of their induction and ongoing training. Representatives of the organisation will be expected to comply with the organisation's Confidentiality Policy and Procedure, even after their period of service has ended.

Breach of confidentiality

- 1.6 Confidentiality will only be breached in clearly specified circumstances (see further below). Any other breaches of confidentiality will be treated as disciplinary matters.
- 1.7 No confidential issue should be discussed with, or revealed to, any person or organisation outside Lymphoma Action, except:
- with the express permission of the person or persons seeking advice or support;
 - where the staff member, trustee or volunteer believes that there is a real or perceived threat of an act of terrorism;
 - where the staff member, trustee or volunteer believes that the person is imminently intent on an act of self-harm or of significant harm to another person;
 - where the staff member, trustee or volunteer believes that the person has committed an act of harm or abuse to him/herself or to another person either recently or at some time in the past;
 - where there is any other safeguarding issue to be dealt with in line with our safeguarding policy.
- 1.8 In cases outlined above, these principles will be as follows:
- in the course of discussion, if the staff member, Trustee or volunteer feels that information is likely to be revealed that could make continued confidentiality impossible, s/he will immediately inform the person of the implications of continuing to reveal such information.
 - in some cases, it may not be possible or appropriate to notify the person that confidentiality will be broken and the appropriate authorities informed. In such cases, the decision to do this should be noted in any incident form, along with supporting rationale for the decision.
 - where information is to be revealed to any individual or organisation outside Lymphoma Action, the exact nature of such information and to whom it is to be revealed must be disclosed to the person (if this is reasonable) and a record kept of such communications. Staff members, Trustees and volunteers will regard it as a priority to support and encourage people to reveal such information for themselves, however, this does not absolve Lymphoma Action or its representatives from disclosing the information to the appropriate authorities (in line with its other organisational policies, most notably the Child and Vulnerable Adult Safeguarding Policy).

2. Confidentiality

Definition

- 2.1 Confidentiality involves the careful and sensitive handling of personal information about people affected by lymphoma, service users or supporters and the issues they discuss with Lymphoma Action staff (be they Trustees, staff members or volunteers). It also covers personal information of Lymphoma Action volunteers, who are often service users and supporters, as well as the appropriate disclosure or sharing of that information to or with other Lymphoma Action staff, or external contacts, in specified circumstances.
- 2.2 Confidential information includes all personal, sensitive and identifying information about people affected by lymphoma, service users or other contacts, including the fact that Lymphoma Action has had contact with that person. This also covers the information about their circumstances and the issues facing them and their family/friends. It may also be considered to include IP addresses for anyone contacting the charity by electronic means.

3. Confidentiality issues in relation to Lymphoma Action's work and activities

- 3.1 Confidentiality issues arise in many aspects of Lymphoma Action's work in informing and supporting those affected by lymphoma. The practical application of Lymphoma Action's Confidentiality Policy and Procedure in relation to specific services is dealt with below.

a) Helpline Services

Helpline Services answer enquiries via phone, email and live chat and offers support, signposting and information. To do so appropriately, safely and comprehensively, it is often necessary for Information and Support Officers to have a degree of knowledge of the personal circumstances and health of the enquirer. However, callers or enquirers can choose to remain anonymous.

Helpline Services are confidential and nothing told to the Information and Support Officers will be shared with any other organisation or individual outside Lymphoma Action without express permission, other than in specific situations such as suicide, safeguarding and acts of terrorism or otherwise required in law. However, there are exceptional circumstances (listed under 1.7) where confidentiality will be broken, with or without the knowledge and permission of the enquirer.

However, on occasion Information and Support Officers discuss enquiries with members of the organisation's Medical Advisory Panel or Nurse Forum in order to verify or obtain further information that has been requested. The individual is notified of this, and their permission is sought. Further, their identity and any information that may identify them is kept confidential, unless permission has been given for details of their case to be used.

Helpline calls are not recorded. It is possible for the staff member to access the telephone number of the person calling via the telephone handset (this is not automatically visible).

However, this is not routinely done or recorded. The exception to this is where confidentiality is

likely to be breached. Under this circumstance, permission does not need to be sought from the individual (and is unlikely to be given anyway).

Live chat transcripts are stored through the information email inbox electronically for 12 months for training, monitoring and evaluating the levels of enquirer satisfaction, and in the case of any queries from the individual. In most cases the helpline staff are able to see the geographical area of the service user, any previous live chats and website use, activity on the website etc during the chat, and IP address. Individual's do not have to give their name or email address to use the Live Chat service, although many people will do so. This information is not recorded by Lymphoma Action, other than via the transcripts automatically sent via Live Chat. The individual's name and address will only be requested, recorded and stored in addition, if they request for information to be sent to them in the post, and in this case only the name, address and fulfilment details will be recorded on the individual's CRM record (and not the call details).

Email enquiries will contain the individual's email address, and may contain varying amount of personal information. Emails are stored through the information email inbox electronically for 12 months for training, monitoring and evaluating the levels of enquirer satisfaction, and in the case of any queries from the individual. This information is not recorded by Lymphoma Action, other than via the email. The individual's name and address will only be requested, recorded and stored in addition, if they request for information to be sent to them in the post, and in this case only the name, address and fulfilment details will be recorded on the individual's CRM record (and not the email/email content).

We never send out information to a third party – we only send information to the individual who contacted the service. Occasionally more than one person may contact the service regarding the same case. These calls are treated as entirely separate from each other and confidentiality is strictly upheld.

Caller or enquirer information is recorded for the purpose of responding to enquiries and sending out requested literature. This information is kept on a secure electronic database. Any handwritten information is stored in locked drawers, and destroyed (confidentially shredded) at the end of each day.

When calls are made from the helpline office, the helpline number is withheld on the individual's handset. Further, the helpline number does not appear on the individual's phone bill.

From time to time, Lymphoma Action receives visitors from other organisations, other teams within the charity, and volunteers. Anyone visiting the Helpline who might be in a position to hear or see details of enquiries will be asked to complete and sign a confidentiality agreement (see Appendix 2).

There are various instances where confidentiality will be broken with or without the individual's consent or knowledge. These include on suspicion of risk of suicide, safeguarding and acts of

terrorism or where otherwise required in law. Here the staff member dealing with the enquiry will need to follow the Helpline policies and procedures and the Helpline Services protocol for handling such calls, and complete an incident form. They will discuss the situation with an SMT member, who will consider whether there is a need to breach confidentiality and inform the relevant authority. In such cases, disclosure to a third party will be made with or without the knowledge or consent of the individual enquirer. (See section 4 of this policy).

b) Volunteers

Lymphoma Action's Confidentiality Policy and Procedure applies equally to volunteers as it does to other members of staff. Lymphoma Action staff and volunteers may gather sensitive and personal information when supporting people affected by lymphoma, or volunteering at activities with service users and supporters. This information may be required in order to ascertain what kind of support the individual or carer needs. It must not be given or spoken to anyone who is not another Lymphoma Action staff member or official volunteer without express permission. This duty of confidentiality continues after volunteer involvement with the charity has ended.

All volunteers sign a Volunteer Confidentiality and Data Protection agreement (appendix 4) committing to follow all processes and instructions given to them during their induction, and within the information and guidance that outlines their confidentiality responsibilities.

Every volunteer has a named Lymphoma Action staff contact who they can discuss the charity's confidentiality policy and procedures with. Volunteers will need to discuss any volunteering concerns and issues with their staff contact, including if they need to talk about a difficult or emotional situation that may affect them as a result of their volunteering activity. This should normally be done without disclosing confidential or personal information, to preserve confidentiality as much as possible.

If it becomes necessary to share confidential information, the Lymphoma Action staff member will take responsibility for their disclosure of this information. If a volunteer has a safeguarding concern for an individual or third party, this should be reported straight away to their staff contact, or a Lymphoma Action staff member, following Lymphoma Action's Safeguarding Policy and Procedure.

Lymphoma Action also protects the confidential and personal information of its volunteers. (Refer to 5 in this document).

4. Breach of confidentiality

- 4.1 The initial assumption is that confidentiality will not be breached. Staff members, Trustees and volunteers may share confidential information with other, appropriate staff, only for the purposes of furthering information and support needs of people affected by lymphoma and other service users. All staff should ensure that no discussions relating to an individual service user take place in public areas. In addition, all staff should ensure that the principles of confidentiality are followed

within the confines of the homeworking environment and that confidentiality is respected. Employees should not have a smart device such as 'Alexa' on while working or should ensure that the highest security setting is activated to ensure confidentiality around work and helpline conversations. However, confidentiality may be breached in the following circumstances.

Serious risk to the health and safety of any person (adult or child), including child and vulnerable adult safeguarding issues.

- 4.2 Confidentiality may be breached by staff and volunteers where there is the suggestion of serious harm or a substantial risk of serious harm to the health and safety of any person (adult or child). This also includes any indication of possible terrorist action (against a person, persons or location). Any decision to disclose information on these grounds can only be taken by the chief executive or a member of the Senior Management Team. Where such a decision is taken, the relevant information will be disclosed to the appropriate authorities. Where the matter concerns a possible terrorist action, the relevant emergency services must be alerted immediately. It should be noted that such breaches will be made with or without the knowledge and consent of the individual.
- 4.3 Any person indicating that they wish to disclose their own abuse or violence towards a child or vulnerable adult will be warned by the member of staff or volunteer working directly with that person that anything they say maybe passed to a relevant authority. The staff member or volunteer receiving such information should bring it to the attention of their line manager or staff contact at once, who will take it up with the chief executive or a member of the Senior Management Team, who will then pass the details to the police, health or social services, or other agency, as appropriate. It should be noted that such breaches will be made with or without the knowledge and consent of the individual.

Reporting discriminatory language or behaviour

- 4.4 Lymphoma Action takes its duties in tackling anti-discriminatory behaviour and language seriously. Where, in the course of supporting a person affected by lymphoma, or other service user, a member of staff, trustee or volunteer perceives a comment or behaviour to be prejudiced or discriminatory, then this should be raised with a line manager, a member of the SMT or the chief executive. Consideration will then be given as to whether an official report should be made to the police and/or whatever other action is appropriate.

Requirement by court/police

- 4.5 Lymphoma Action has a legal obligation to provide information to a court of law or the police, as required, further to those proceedings or investigations.

Inspection by a statutory body

- 4.6 Lymphoma Action operates as a charity in England and Wales, and in Scotland. As such, it is subject to regulations and standards which, among other things, may require inspection, investigation or review of its work and policies and practice. While a breach of confidentiality may occur as a result

of such inspection, investigation or review, the Charity Commission and the Office for the Scottish Charity Regulator work under their own confidentiality policies.

5. Storage of information and records

- 5.1 As most of the information held on supporters, service users and volunteers is personal and/or sensitive, this information is kept securely on computers and servers, protected by firewalls and passwords, and by encryption and password protection in the case of portable devices. Our data protection, security and home working guidance documents include the measures to be taken to minimise any security risks. In the case of manual records, these files are kept in locked cabinets. In the case of our IT systems, information from the central server is backed up daily and kept in a separate location away from the office each night.

All manual and computerised records about people affected by lymphoma, other service users and contacts will remain the property of Lymphoma Action, and are subject to the General Data Protection Regulation (GDPR) which came into force in May 2018, the Data Protection Act 1998 (and any subsequent amending legislation). Information and records will be kept securely and information will not be passed to a third party without the prior authorisation of the supporter contact concerned (unless a valid legal exemption applies).

6. Statistical and monitoring information

- 6.1 From time to time, Lymphoma Action needs to make health organisations, the media and general public aware of the types of issues faced by those affected by lymphoma. In these instances, statistics on the type and number of people using our services may be disclosed. Also, for internal monitoring and quality assurance purposes, Lymphoma Action will compile statistical information for its own use. Where statistical data is collated, reviewed and published, this will usually be done so using anonymisation of data, unless otherwise where permission would be explicitly sought from the individual(s) if refers to.

7. Case studies

- 7.1 Case studies are used by Lymphoma Action to illustrate issues in the course of its work influencing or informing government, the media or the general public, or for fundraising purposes. These will either be anonymised, where appropriate, or may use a first name (either real or fictitious), subject to relevant consent from the subject of the case study. However, full names or locations of where the person concerned lives will not be given out and the person concerned will always be asked first to verify that s/he gives their agreement for Lymphoma Action to use their experiences anonymously or with a first name included. Case studies may also be used in staff training, however, the person's location will be changed and pseudonyms will be used.

8. Media requests

- 8.1 Occasionally, the media requests case studies to illustrate a particular topic that has recently hit the headlines. In this instance, Lymphoma Action will only contact people within its supporter networks

who may be interested in taking part. Those who are contacted are informed about the request and encouraged to contact the relevant media directly if they feel it is appropriate to their situation. This is the preferred method of introduction, but on occasion supporters have asked us to make an introduction to the journalist on their behalf by way of an email exchange, or the provision of contact details. In this instance, we will facilitate an introduction but only after we have received formal written consent from the supporter for us to do so (usually in the form of an email) for us to keep on record. Contact details of supporters are never given to the media outlet directly without prior consent.

- 8.2 If Lymphoma Action feels the request is totally inappropriate (e.g. there is undue sensationalism or a risk of disclosing identifying information about someone, a lack of taste, or a conflict with Lymphoma Action's principles or values) for people affected by lymphoma, service users or supporters, no attempt will be made to follow through with the request.
- 8.3 In addition, the media outlet may need to be made aware of the difficulties associated with the inclusion of photographs of individuals if they are requesting them. If Lymphoma Action uses photographs of any of the people it has helped, other service users, supporters or volunteers in publicity material, it always ensures that a photo consent form is completed and permission given. The media outlet will need to be informed that this process needs to be followed before we can release any photographs, which may exceed the timescale of their deadline.

9. Express consent to the disclosure of information

- 9.1 For people affected by lymphoma whom the organisation has helped, or other service users or supporters of Lymphoma Action who agree to share information or release their details to anyone else, this must be noted on their database record.

10. Access to files

- 10.1 All people affected by lymphoma whom the organisation has helped, or other service users or supporters of Lymphoma Action have a right to see any files or records containing information about them. An individual's request to access their personal data is commonly referred to as a 'Subject Access Request' – which can be made verbally or in writing and the charity have one calendar month to respond to a request. Under GDPR, individuals also have a number of additional rights related to their data, for example, the right to have inaccurate personal data rectified or completed (if incomplete), or 'the right to be forgotten' (which is not an absolute right and only applies in certain circumstances). Anyone wishing to see their information or exercise any of their rights under GDPR should contact:

Ropinder Gill, Chief Executive
Lymphoma Action, Unit 3, Bell Business Park, Smeaton Close, Aylesbury HP19 8JR
Tel: 01296 619400

11. Ensuring the effectiveness of the policy

- 11.1 All new and existing staff, Trustees and volunteers will receive a copy of this policy during their induction and ongoing training.
- 11.2 This policy applies to all Lymphoma Action staff, Trustees and volunteers. Any amendments proposed must be agreed by the Chief Executive and, where they represent significant policy change, be then approved by Lymphoma Action's Board of Trustees.

Appendix 1 (over)

Appendix 1

Confidentiality Agreement for Staff

The work of Lymphoma Action with people affected by lymphoma, other service users, supporters and contacts, and all information known or recorded about those people, is strictly confidential. This agreement sets out the arrangements you will have with Lymphoma Action regarding that confidentiality, and should be read with Lymphoma Action's Confidentiality Policy and Procedure.

As a condition of your employment, you are prohibited from discussing with, or passing on this information (either verbally, in writing or in any other documented form) to, any third party not connected with Lymphoma Action. In this respect, even the "casual" disclosure that a particular person has contacted the organisation, would be considered a breach of confidentiality.

While the initial assumption is that confidentiality will not be breached, information about a person affected by lymphoma, or other service user or contact, may be given to a third party with the prior permission of the person concerned or if authorised by the Chief Executive or a member of the Senior Management Team (where there is either the suggestion of serious harm, the substantial risk of serious harm, or where serious harm has occurred, to the health and safety of any person or where otherwise required in law). Where such a decision is taken, the relevant information may be disclosed to the appropriate authorities.

The denial of the person's, services user's or other contact's consent is not a bar to disclosing information within Lymphoma Action (i.e. to other staff members for the purposes of securing additional or appropriate information, advice and support for that patient, carer or service user).

You should be aware that if a person affected by lymphoma or other service user is involved in court proceedings, court rules prohibit the disclosure of court documents, except in certain circumstances or with the permission of the court.

Your obligation to maintain confidentiality continues even after your employment by, or your role with, Lymphoma Action has ceased. Any documentation or records (digital files or otherwise) received in the course of your work or role, must be returned to Lymphoma Action's offices (or securely destroyed with agreement).

In addition, during the course of your work you will have access to confidential information about the work of Lymphoma Action, its development and the conduct of its staff. Care and discretion should be exercised at all times if discussing these matters outside of Lymphoma Action.

By signing this document, you are accepting this agreement and agreeing to carry out your work or role in accordance with Lymphoma Action's Confidentiality Policy and Procedure and any other related policies and procedures, including the organisation's Safeguarding Policy, and Data Protection Policy.

Failure to comply with the Confidentiality Policy and Procedure will be treated as a disciplinary matter. In relation to all questions about confidentiality, the Chief Executive or a member of the Senior Management Team should be consulted without delay.

Signed:

Date:

Name of new member of staff:

Position:

Date of appointment:

Appendix 2

Confidentiality agreement – Helpline Services



Information and support - confidentiality agreement

All details of contacts* that come into the Lymphoma Action Information and Support Services team, by all methods including helpline, email and Live Chat, must be treated as confidential. This means that any staff member, volunteer or visitor must not discuss the nature or details of specific calls outside of the Information and Support Services team.

Anyone who visits the Information and Support Services office, whether to specifically 'listen in' to contacts or who may hear the content of such contacts in passing, will be asked to sign the following confidentiality statement.

Anyone who has any concerns following 'listening in' to services should raise this with the Information and Support Services manager.

Please read the following and sign to show your understanding and agreement.

I agree that I will not disclose to or discuss with anyone outside of the Information and Support Services team any information from the content of contacts of which I become aware.

Signed:

Print name:

Date:

Helpline representative:

* Contacts refers to any service-user who accesses the information and support team services, whether by helpline, email, Live Chat or any other method.

Confidentiality agreement for volunteers

Volunteer Confidentiality & Data Protection Agreement

This agreement sets out your responsibilities as a volunteer for confidentiality and data protection throughout your volunteering with Lymphoma Action and after it ends.

Confidentiality and data protection are covered in general volunteer inductions and in role-specific inductions. You will be provided with confidentiality and data protection information, guidance and training, as required for your volunteer role, including the charity's confidentiality and data protection policies and procedures. Should you have any questions or concerns, your designated staff contact is here to support you to understand your responsibilities as a volunteer and discuss the charity's confidentiality and data protection policies and procedures with you.

Lymphoma Action has a legal and ethical duty to protect the confidential information of everyone we engage with, and to process the personal data of everyone in contact with the charity according to the Data Protection Act, which implements the General Data Protection Regulation (GDPR).

As a cancer charity, many of Lymphoma Action volunteers, as well as service users, other beneficiaries and supporters, disclose personal data about their health and personal information about their lives during the course of their contact with the charity. This requires an additional responsibility on the charity to keep this information confidential. **These duties and responsibilities extend to every volunteer and continue after your volunteer involvement with the charity has ended.**

Volunteers have a common law duty to maintain the confidentiality of information you have access to during your volunteering, and a legal duty to abide by the Data Protection Act where your volunteer role involves having access to the personal data of service users, beneficiaries, supporters, other volunteers and staff.

Lymphoma Action, as a data controller, is liable for breaches of confidentiality and data protection. That's why we have charity policies, guidance, instructions and training in place to mitigate against accidental breaches. As a volunteer you will not be personally liable for accidental breaches made when carrying out your responsibilities in line with the charity's policies, guidance, instructions and training.

By signing below you acknowledge you have read and understood the mutual expectations and confidentiality and data protection agreements.