



Buddy Service Buddy Handbook




Thank you!

Without your valuable time as a volunteer, we simply wouldn't be able to reach as many people as we do, to offer them a safe and confidential service where they can share experiences, ask questions and help each other live with and beyond lymphoma.

From all of us at Lymphoma Action we'd like to say a huge thank you for being a Buddy. We're here to support you every step of the way and make sure you have a meaningful volunteer experience.

We hope you have a truly rewarding time with us in providing support for other people affected by lymphoma.

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Welcome and introduction

Lymphoma Action's mission is to make sure no one faces lymphoma alone and everyone affected by lymphoma receives the best possible information, support, treatment and care.

We do this by informing, supporting and connecting anyone affected by lymphoma in the UK.

Your time as a Buddy is valuable in helping us achieve our mission by:


- Creating a safe and confidential service for people affected by lymphoma to share their experiences with someone who understands what they are going through.
- Offering peer-support, using your personal experience of lymphoma to support others to feel less isolated and more able to cope with living with lymphoma.
- Connecting people with information and other support services available from Lymphoma Action.



I chose to be a buddy as I received wonderful support from peers when I was ill and I wanted to do the same for others. Without peer support my questions and worries would have gone unanswered.

How to use this guide

Our *Buddy Handbook* is a guide to Lymphoma Action's Buddy Service and covers various aspects of the service and requirements of being a Buddy. For new Buddies this Handbook complements your volunteer induction and the ongoing support you'll receive from us. For existing Buddies, we hope this will include useful reminders for you.

The practical guidance and information here aim to ensure you have a meaningful, safe and enjoyable volunteer experience with us as a Buddy. The role specification for Buddies, and general guidelines for the service, are included in **Your role as a Buddy** and **Appendices** .

It is important that you read, understand and follow this guidance and use this Handbook as an ongoing reference. For general information about volunteering with us, please refer to our online resources section: lymphoma-action.org.uk/vr

This guide has five sections:

1. **About the Lymphoma Action Buddy Service**
2. **Your role as a Buddy**
3. **Guidance for supporting individuals**
4. **Key resources summary**
5. **Appendices**

You will find signposts to each colour-coded section, and the digital version contains links to move to that section or the specific information listed. We've also included links to our website, where relevant.

If you have any questions or concerns about your role or the service, the Buddy Service team and Volunteering Development Manager are available to talk this through. So please don't hesitate to get in touch.


Buddy Service team:

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Senior Information and Support Officer

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1.

About the Lymphoma Action Buddy Service



In this section, you will find:

- Details of the Buddy Service
- Commonly asked questions

The Buddy Service is one of Lymphoma Action's key support services, offering direct peer-to-peer support for people affected by lymphoma.

Our Buddies come from all over the country, and have a wealth of different experiences. Some of our Buddies have had very few links (for example, if they have a rare lymphoma or rare experiences where we have not had any requests from individuals to make a link). Other Buddies may have had several links, over a period of time. Whether a Buddy has had no links, or many links, we greatly appreciate that they continue to volunteer as a Buddy to be there when they are most needed.

All of our Buddies have personal experience of lymphoma: some will have or have had lymphoma themselves, or they may be a family member or carer of someone with lymphoma. All of them use their personal experiences to support other individuals affected by the condition.

Our Buddies are not medically trained, and they are not trained counsellors. Although some Buddies may have a medical or counselling background, this is not something that we would ask them to disclose or use within their links.

Our Buddies do not give advice, and can only share their personal experiences. This is really important because the Buddy Service is **not an advice service**. If any of our Buddies give advice this could lead to legal issues (if the person acts on the advice) and this would be the responsibility of the Buddy not Lymphoma Action (as we have told Buddies that they must not give advice).


See **Your role as a Buddy** (page 12) for a role description.



Commonly asked questions

What does the Buddy Service offer?

The Buddy Service offers individuals an opportunity to talk to, and be supported by, a Buddy who has been through similar experiences. We often describe this as 'peer support' where an individual can talk to someone 'like them'.

Full details of what the service offers and, importantly, doesn't offer, can be found in the [Appendices](#)  and on the website: lymphoma-action.org.uk/buddy-service

Why do people become Buddies?

Many of our Buddies join the service because they want to use their experiences to help and support others, and 'give back'. For some, they want people to have the support that they had themselves, and others want to support people because they felt that this type of support was missing for them.

Is this a befriending service and can we meet in person?

The Buddy Service is about talking to someone who has been through a similar experience and understands how it can feel to have lymphoma. The service offers short-term contact, and is offered by phone or email. **It is not befriending and is not intended as a long-term relationship.**

Befriending is a different type of service from what we offer. Befriending might include regular calls or visits to someone at home, and sometimes helps with loneliness and isolation. There are other organisations that offer befriending and, if appropriate, we would try to signpost to this type of service through our helpline.

Our Buddies **do not** meet with individual's in person, for a number of reasons. A Buddy won't necessarily be geographically close to the individual. To offer a face-to-face service would need a different type of structure and training. For example, we would need to be able to ensure that our Buddies were safe if they are meeting people on a one-to-one basis. Also, speaking to someone that they don't know and won't meet can actually be beneficial for some people, and encourage them to talk more freely than they otherwise would.

Offering support by phone and email also gives us more flexibility, and means that we can offer the service to more people, and our Buddies can offer this role from home.

Do you match on age and gender?

This depends on the preference of the individual requesting the link, and sometimes it is relevant to the content of what they want to talk about. For example, the individual might want to talk to someone of the same gender if they want to talk about fertility issues, or of a similar age if they want to talk about work or retirement. We will always ask the individual if they are happy to talk to a different age group or gender, and we'll try and find a Buddy to match their preferences.

What do you know about an individual before you look for a Buddy for them?

When someone first requests a Buddy, we always have a conversation with them on the phone (through the helpline) to find out what they are looking for. We ask them many of the same questions as you provide in your experiences form: what lymphoma they have, what stage their lymphoma is, whether they have had treatment and so on. Importantly, we talk to them about what they would like to talk to a Buddy about. For example, if it is about treatment, side effects or lifestyle issues. We also ask practical questions about their contact details, how they would like to connect with the Buddy (by phone or email), and whether they are happy to talk to someone of a different age or gender. We talk to the individual about the service: we explain what the process is for linking with a Buddy, and explain what the service offers and does not offer.

What do you match Buddy's and individuals on?

When we look for a Buddy for an individual, there are key things that we look for.

Usually, the most important thing is that the Buddy has the same type of lymphoma. This is because different lymphomas behave differently and often have different treatment options. In rare cases, if we can't match on lymphoma type, we will try and find another close match in other areas (such as treatment type). We will always explain to the individual if we can't find someone with the same type of lymphoma, and check if they are happy to be matched with someone who has a different type.

The next step is to match on what the individual wants to talk about. For example, they might want to talk about treatment or side effects, so we need to match with a Buddy who has had the same type of treatment. If they want to talk about lifestyle issues, such as work or relationships, we look for a Buddy with similar experiences.

Our aim is always to get as close a match as possible, and we always discuss with both the potential Buddy and the individual why we think they would be a good match. If a close match isn't possible, we always try and find 'as close a match as possible', and give the individual the choice whether they would like to go ahead with the link or not.

How important is a close match?

We feel that it is really important, particularly because lymphoma can vary so much from one person to another, and things like how lymphoma presents and the treatment options used, will depend on the individual type of lymphoma. For example, individuals often want to talk about the particular type of chemo they are about to have, so linking to a Buddy who has had a different sort of chemo would probably not be helpful.

We've also asked both Buddies and individuals how important they think it is to get a close match, and the response we receive is that they think it is important too.

Do you match by location?

No, we don't match by location. Our service is available to anyone in the UK, and our Buddies are all within the UK. However, we don't match by location as this is usually not relevant to the person's lymphoma. We discourage our Buddies from sharing their location as the service does not offer face-to-face support.

There is a possibility that Buddies might meet the individual they are linked to, for example at a Lymphoma Action Support Group or event. In this situation, we ask Buddies not to mention the link unless the individual does, and not to talk about the details of the link in this situation (for reasons of confidentiality).

1. About the Lymphoma Action Buddy Service

Can you always match with a Buddy?

No, sometimes it is not possible to match with a Buddy. This is usually because we don't have a suitable match for the individual's situation. Although we will always try and make a very close match, sometimes this is not possible but we might be able to match on some criteria. In this case, we would explain to the individual what we can and can't match on, and ask whether they would like us to make the match even though it is not a 'perfect fit'. We will always leave it to the individual to make the choice.

Do people ever change their minds about a link?

Unfortunately, yes! There can be many reasons why someone might change their mind about requesting a Buddy. For example, they may contact us at a time when they feel the need to talk about what is happening is urgent, but if things move on for them they might feel that they no longer need a Buddy.

Sometimes we find a suitable Buddy who is available but when we contact the individual they have changed their mind. Although it can be frustrating for the Buddy, it is important that the individual has this choice. In this case we always let the Buddy know.

On some occasions, an individual changes their mind about contacting a Buddy *after* we have made the link. We ask individuals to let us know if they decide not to make contact with the Buddy. If they let us know, we let the Buddy know so that they aren't waiting to be contacted. On some occasions we find out that the individual hasn't made contact when the Buddy tells us that they haven't heard from them!

Can someone request a Buddy on behalf of someone else?

We don't accept requests for a Buddy on behalf of someone else. This is for several important reasons. Firstly, we need to be sure that the individual wants a Buddy and that someone else, however well-meaning, is not making this decision for them. If the individual doesn't want a link they would be unlikely to contact the Buddy.

Secondly, we are not able to share information about an individual with a Buddy without their permission, nor give a Buddy's details to someone else. So, we need to talk to the individual directly to confirm permission to share the information.


Lastly, we need to talk to the individual directly to understand their situation, needs and what they would like to get from the service. For this reason, we need to talk to the individual, via the helpline, to understand these issues.

What do Buddies know about an individual when the link is made?

We give the Buddy the individual's first name (we don't share surnames) and how they want to get in touch. We tell them relevant information about the individual's situation, why they want a Buddy and what they want to talk about. We also explain why they would be a good match.

We make sure individuals are aware that we will share relevant information with their potential Buddy. We also check if there is anything specific that they would like the Buddy to know about them. For example, any communication needs.

Once the individual has confirmed that they want to go ahead with the link, we send the Buddy an email confirming this.

See [Appendices](#)  (page 38) or the sort of information we ask for and share with Buddies.

What do individuals know about their Buddy when the link is made?

We give the individual the Buddy's first name (we don't share surnames). We tell them a little about the Buddy's relevant experiences, and also about any *differences* in experiences, so that they can decide if they think it is the right link for them.

If the individual would like to go ahead with the link, we give them the Buddy's contact phone number or email address (depending on how they want to contact the Buddy), and details of days or times when the Buddy is available.

We confirm the details of the link in an email to the individual, and include a link to the service terms and conditions on the website.

Why do you give the *individual the Buddy's contact details (and not the other way around)*?

We give the individual the Buddy's contact details so that they can decide whether to get in contact or not, when they are ready. Some people decide, after the link is made, that they don't want to make contact after all. By doing this, we are putting the 'ball in their court' so that they can make contact when it feels right. Our Buddies have confirmed that they think this is the appropriate way to share contact details.

We ask individuals to get in contact with their Buddy within two weeks, and often suggest that they text or email first to arrange a convenient time to speak.

As we are sharing personal phone numbers and emails, we suggest that Buddies consider creating a new email address to use solely for their Buddy links (for example BuddyJohn@gmail.com) so that they don't use a personal email.

Are there issues of confidentiality if you share emails and phone numbers?

We make it clear to Buddies and the individuals using the service that we will share first names and contact details, and some personal information. This is a requirement for identifying a Buddy, and putting the Buddy and individual in touch with each other. Because both parties know that we share this information, this gives us consent to do so. We don't share more information than is needed for us to deliver the service. For example, we don't share surnames as this is not needed in order to make a link. (Some people have an email address which includes their surname, so we suggest that Buddies use a new anonymous email address for this purpose. See previous question.)

We encourage Buddies and individuals to avoid sharing more personal information than is needed, and this is at their discretion.

We also require that any information that is shared during a link is deleted or destroyed after the link is completed. For example, deleting emails or text messages (see page 21).



I hoped that I might be able to support and empathise with those who might be travelling on a similar journey to mine.

2.

Your role as a Buddy




In this section, you will find:

- Description of the Buddy role and remit of the service
- Details of how we make links
- Details of how we support you
- Policies and procedures

We are grateful to all of our Buddies for enabling us to offer this important peer-support service. Without you we would not be able to support people in this way.

To ensure its consistency and integrity, we have various documents that ensure the service is used appropriately, and to protect the safety and wellbeing of Buddies.

All of these documents can be found in the [Appendices](#)  (page 38).

1. Role description

The role description for Buddies outlines the service they provide and the key skills and experience needed for the role. This description was reviewed and updated in January 2020.

2. What the service offers (and doesn't offer)

This document outlines the remit of the service, and what people looking for a Buddy can expect from the service and from Buddies. It also includes important information about the boundaries of the service.


3. Terms of service

This document gives more detail than document 2, and explains how to use the service and what our expectations are of people who use the service. We explain this information to individuals who request a Buddy, and check that they have understood the terms of the service. We also include a link to this document as a reminder, in the email to confirm their Buddy link.

This document is also helpful for Buddies if they need to remind an individual about the remit of the service. Buddies are also encouraged to talk to us if they would like to discuss any issues around the service, or how to support individuals.

4. Our expectations of Buddies

This document outlines the service that Buddies are expected to offer, and includes guidance on how to deliver this. Importantly, it sets the boundaries of the service that all Buddies must work within in order to remain a Buddy for us. This document is available on the website so that individual's using the service know what to expect from a Buddy.

All of these documents can be found in the [Appendices](#)  and on our website at: lymphoma-action.org.uk/buddy-service

Individuals can speak to someone who has been through the situation they are facing and come out the other side. In most cases they can hear that their concerns were also those the buddy faced earlier and learn how they got through them.



The remit of the service

The Buddy Service has a clear remit and boundaries, many of which focus on supporting our Buddies.

The service is short-term, and not a counselling, therapy, befriending or 'friendship' scheme.

We suggest that individuals can contact their Buddy up to six times or over a period of three months. This is a guideline, as the number of times they contact you will depend on their situation, and sometimes slightly more contact may be helpful. The individual can discuss this directly with you to ensure that any continued contact is appropriate and mutually convenient.

Buddies are under no obligation to extend the time that an individual is in contact. We offer this guidance so that you are not over-whelmed, or in case gently giving some boundaries might be helpful for the individual.

If long-term contact continues (for example, for a year or more) this is outside of the remit of the Buddy Service and would not be recognised by us as a Buddy link. There may be times when an individual needs to be gently reminded of this.

Buddies must make it clear that the experiences they share are their own (and they recognise that other people will have other experiences). We explain this to individual's but it may be helpful to remind them.

Buddies must not give advice (including medical advice). This is important because if an individual were to act on advice given by a Buddy, this could have a negative impact on the individual, on the Buddy and on Lymphoma Action. The Buddy Service does not offer advice, and any Buddy giving advice will be held responsible for this. Lymphoma Action will not take responsibility for any advice that you give.

When you are in contact with an individual

When we make a link, we give the individual your contact details. We ask them to make contact with you within two weeks either to talk, or to arrange a time to talk. If the individual has contacted you and left a message requesting you to get in touch, you can then contact them (we just ask that you don't make the *first* contact).

We have a list of useful organisations that you can signpost individuals to (that we have checked for suitability). If you signpost to an organisation please make it clear that it is not a recommendation, and that we cannot guarantee that it will be helpful. Please don't signpost to organisations not on the list (as we have not checked their suitability). However, if you would like to suggest any organisations to us to consider adding to the list, please do let us know.

The list of useful organisations can be found on our website at:

lymphoma-action.org.uk/useful-organisations

When we ask you to call us

There are various situations where we ask Buddies to contact us. This includes, but is not limited to, the following.

If there are any changes to your contact details (as this is how we will get in touch with you and also what we pass on to an individual if we link with you).

If there are any relevant changes in your health circumstances. This is to support your wellbeing and ensure that we give you time to focus on your own needs outside of the service. For example, if you are having treatment we would not make any links with you during your treatment and for a few months afterwards. In this instance we would refer to you as 'resting' to ensure that we don't contact you about potential links until you feel ready.

If there are any changes in your experiences that you can share, which might mean that there are more opportunities to link with you because of these experiences.

If there are any other reasons why you would not be able to take on a link, for example, you are busy or feel unable to help (so that we don't approach you about links if you are taking some time away from the service).

When to refer individuals back to Lymphoma Action's Helpline Services

If we have any concerns about whether the service is appropriate for an individual who requests a link, we will usually signpost them to a more appropriate service. However, there are various situations where we would ask you to refer individuals back to our Helpline Services. This includes, but is not limited to, the following.

They are dependent on you or on the service (they appear to rely too heavily on you or the service, or seem unwilling to end the link).

They appear to be misusing or abusing the service (for example, they repeatedly contact you outside of the service boundaries, or they aren't using the service appropriately).

You feel the link is not appropriate, or you are not able to fulfil the link request for any reason.

They contact you after the link has ended or after a long period of time.

You are concerned about their medical or emotional wellbeing. It may also be appropriate to suggest that they contact their medical team.

You are concerned that they could be suicidal. It may be appropriate to suggest that they contact specific support organisations such as the Samaritans.

They disclose information that you are concerned is, or could be, a safeguarding issue.

You are concerned for any other reason.

If you have any concerns, we suggest that you contact us and talk this through. This is important for the individual, but also for *your* wellbeing. If appropriate, we will make contact with the individual (or in the case of safeguarding issues we would be legally obliged to take this further).

The confidentiality of the Buddy Service means that you can share with us anything that might be concerning you (see page 22).



I enjoy when an individual feels reassured after voicing and articulating their concerns, fears and apprehension, and being able to show that there is always hope.

How we make Buddy links

There are various stages we go through when making a link between an individual and a Buddy. Here we outline each step.

1. An individual requests a Buddy

If an individual would like a Buddy, they need to speak to the helpline. This request might come up naturally through a helpline call, or an individual may be asked to call the helpline, for example, by one of our other services.

To be able to understand the individual's particular circumstances and identify what sort of support they are looking for, the helpline team have an initial chat with them. The team can tell them about the service and how links are made, and find out the required information in order to look for a Buddy with similar experiences.

2. We look for an appropriate Buddy

Once we have spoken to the individual, we can start to look for a Buddy. The most appropriate Buddy will depend on the needs of the individual, and the individual circumstances we need to match. For example, we usually start by matching on type of lymphoma, and then look at treatment options or lifestyle factors.

We may identify one or more Buddies who may be suitable. We call the Buddies and check if they are available to support the individual (as it isn't always convenient for them). We tell them about the individual's circumstances to see if they feel they would be a close match and appropriate link. We'll also ask them about their availability to be contacted by the individual.

We can't always find a very close match to the individual's circumstances, but will try and find a Buddy who matches on *at least some* of them. For example, there might be a Buddy with a different type of lymphoma but who has had the same treatment that the individual is having. We may speak to the individual again to outline the Buddy's experience - to see if it feels relevant to them - before contacting the Buddy again.

In some, rare, cases we might not be able to find a Buddy at all. This may be because the individual has a very rare lymphoma or they want to talk about an issue and we don't have any Buddies with this experience. In this case, we contact the individual and explain this. We will often talk to them about other support, and invite them to contact our Helpline Services.

3. We contact the individual

Once we have identified a Buddy, we contact the individual. We tell them about the Buddy and why we think they would make a good link. If any of the Buddy's experiences are different, we explain this. **We check whether they would like to go ahead with the link**, and they always have the option to change their mind.

If the individual would like to go ahead with the link we give them the Buddies contact details: their name, and phone number or email address.

4. We confirm the link by email

We confirm the link with the individual and the Buddy by email. We ask the individual to let us know if they decide not to make contact with the Buddy, and that we may contact them in a couple of months to see how the link has been and if they would like any further support. We also remind them of the Terms of service, for guidelines about how to use the service and about confidentiality.

5. If the individual changes their mind

If the individual tells us that they have decided not to make contact, we let the Buddy know. In some cases, the individual decides not to make contact but doesn't let us know. This can be frustrating for a Buddy who is expecting to hear from the individual. However, it is often that the individual has 'moved on' and feels that they no longer need this type of support or has already found the support they need.

6. Getting feedback from the individual

A couple of months after making a link, we often contact the individual to request some feedback on how they are getting on and how the link was for them. This is an important way for us to see how the service is working, and to monitor the impact of the service: what difference it makes to individuals who use it.

We call or email to request this feedback, which individuals can give anonymously via an online survey. It is not unusual for individuals to not get back to us! Although this means we aren't able to get feedback to review the service, it often means that they have moved on and don't feel it is necessary to give feedback on the service.

7. Passing on feedback

If we receive feedback from individuals, we ask for their permission to share it with their Buddy. We want them to be open and honest (including if anything didn't work for them) and so asking for permission to share their feedback gives them option to say 'no'.

Where we have permission to share feedback we pass this on to the Buddy.

8. Supporting the Buddy after the link

We encourage all of our Buddies to get in touch with us if they would like to after a link. This might be to chat through how the link has been, or if it has brought up any issues for them.

Not all Buddies want to get in touch after a link, but this is always an option if they would like to at any point.



How we support you

It is important that our Buddies feel valued and supported. The service sits within the Information and Support Services department, working with the Volunteering Development Manager.

Your Buddy Service team

Sharon and Nicola, our Information and Support Officers, speak to individuals who request a Buddy, and contact Buddies about potential links. You can contact them if you'd like to talk about any links you've had, or if you need to update us about any changes to your condition. They will also get in contact with you if they've had any feedback from an individual you have linked with.

Rona works alongside Sharon and Nicola, as Education and Support Services Manager. She manages the service and supports Sharon and Nicola in their roles. She is responsible for the documentation around the service (for example, this handbook and Terms of service) and leads the training programme for new Buddies.

You can reach us via the helpline on (freephone) 0808 808 5555 between 10am and 3pm, Monday to Friday. By calling the helpline you can use the freephone service, and we'll be able to take your call in the confidential environment of the helpline office. Alternatively, you can email information@lymphoma-action.org.uk and we will email or call you back.

Buddies are also part of our volunteering community. Carly is our Volunteering Development Manager, and supports all of Lymphoma Action's volunteers. Carly is the person to speak to if you have any queries about being a volunteer. You can reach Carly on 01296 619 424 or c.benton@lymphoma-action.org.uk

How we keep in contact with you

As part of the Buddy Service you will receive Buddy Service email updates from us. These will give you news and updates about the service, as well as links and reminders to various documents, such as guidelines for Buddies and the volunteer activity form.

We will get in contact with you if we have an individual for whom we think you would be a good Buddy. We usually try to reach you by phone, but may email if we haven't been able to reach to you.

We encourage you to get in contact with us if your situation changes. This might mean that you have additional experiences you can share, or it might be that you'd like to come off the service (we call this 'resting') for a time and not have any Buddy links.

As a volunteer you will receive a quarterly volunteer e-newsletter with general volunteering updates, and Lymphoma Action news to help you in your role.

How we connect you with other volunteers

We aim to provide opportunities to meet other volunteers, whether that's online or on some occasions face-to-face, so that you feel part of our valued volunteer community.

Our Buddy Closed Facebook Group is available to offer mutual support to one another, in a friendly, supportive environment. Buddies can register for the group at:

www.facebook.com/groups/LAbuddy

Policies and procedures

As a volunteer it is important that you understand, and carry out your role, within Lymphoma Action's policies and procedures, to provide a safe experience for yourself, our service users, other volunteers and Lymphoma Action staff.

Information about your responsibilities as a Buddy are outlined below and are covered during induction training.

Confidentiality and data protection

Lymphoma Action has a legal duty to protect the confidential information and personal data of everyone we engage with, and must comply with data protection legislation, as detailed in our data protection policy. Please refer to our information about confidentiality and data protection on the volunteer resources hub on our website at: lymphoma-action.org.uk/vr

Buddies have a responsibility to, and must always, protect the confidential information and personal data you will have access to through your Buddy links, including that of other volunteers and staff. This responsibility continues after your volunteer involvement with the charity has ended.

Health, safety and wellbeing

Lymphoma Action is committed to providing a safe experience for everyone involved in our work and activities. As part of the charity's legal responsibilities for health and safety and duty of care, we risk assess the Buddy Service and Buddy role, to make sure we provide a safe experience for our Buddies, service users and staff members.

As a volunteer you have a responsibility for your own health and safety too. Please refer to our information about health, safety and wellbeing, which includes volunteering from home, on the volunteer resources hub on our website at: lymphoma-action.org.uk/vr

Your own health and wellbeing should always be a top priority while volunteering. Please be mindful of your own feelings following a Buddy link, and refer to the section **Practical Issues - After a conversation has ended** (page 27).

If you are going through a period of being unwell, or require treatment, please let us know and we will support you to take a break from volunteering.

Equality and diversity

Lymphoma Action is committed to providing equal opportunities for all and to valuing diversity. We value the involvement and contribution of all Buddies and everyone who accesses the Buddy Service. As a Buddy, you have a responsibility to respect the rights and dignity of others and be inclusive and welcoming of everyone you meet during your volunteering.



2. Your role as a Buddy

Safeguarding

Safeguarding is about creating a safe and welcoming environment. Lymphoma Action has a duty to safeguard and protect everyone involved with the charity's work. The charity must act to prevent potential or actual harm, harassment, bullying, abuse and neglect, and respond immediately and appropriately if there is a problem involving any of these.

The boundaries of the Buddy role are in place to promote safeguarding – please refer to **The remit of the service** (page 14).

It's useful to be aware that Buddies are unlikely to encounter any safeguarding issues but you must be aware of what to do in the event of any.

Buddies have a responsibility to follow our safeguarding practices, including reporting any information or concerns you have, or are made aware of, about safeguarding during your link. This may be something an individual discloses to you, or a concern you have about what an individual has shared during a conversation. All reports will be taken seriously and must be made as soon as possible to the Buddy Service team. Lymphoma Action will then take responsibility for any further action required.

If you feel that there is an immediate risk of serious harm, you should report it to the police to prevent the harm, by calling 999. Remember that confidentiality can be broken for safeguarding purposes only.

Our incident report form is in place to detail as much information about the situation as possible and send to the Buddy Service team. You can find a copy of this form on page 58. Please refer to our information about safeguarding on the volunteer resources hub on our website at: lymphoma-action.org.uk/vr

What information we keep about you

To be a Buddy, we need detailed information about you, your condition and your experiences, in order for us to make links with individuals. By agreeing to be a Buddy you are giving us your consent to take, store and use this information in order to run the Buddy Service.

You will have shared your information on our 'Buddy experiences form' via Survey Monkey*. We download this information and keep it in a spreadsheet, in a restricted access folder (that only members of Lymphoma Action staff who are involved in the service can access). If you have been a Buddy with us for a while, you may have completed a previous experiences form. Any additional information from your previous form that isn't included in your new online survey form will be added in.

*If you completed a paper copy of the form we will have added this to our spreadsheet and destroyed the paper copy.

Any notes we make to help us make a link for an individual (usually just your name) are kept securely and destroyed once the link is completed.

We store your personal contact details (your name and address), the fact that you are a Buddy, and a list of people you have had a link with, on our charity 'Customer relationship management' database. This database can only be accessed by members of Lymphoma Action staff, and it is password protected.

Please refer to our confidentiality and data protection information:

www.lymphoma-action.org.uk/vr

How you should handle personal information about individuals

Buddies read and sign a volunteer confidentiality and data protection agreement when they join as a volunteer, agreeing to carry out their role within the procedures for maintaining confidentiality and using personal information.

When we link you with an individual, we will tell you their name and a little about them. We also confirm their first name in an email. We will not give you their contact details as we expect *them* to make contact with *you*.

If the individual contacts you, you are likely to have the following information about them.

- Their phone number and any messages/texts.
- Their email address and emails.
- Any information that they have shared with you during the link (this may be verbal or written, depending on how they contact you).

We ask that you do the following.

- **Don't** share the individual's personal details or details of the link with anyone outside of the Buddy Service.
- **Don't** use this information to your own purposes.
- **Don't** share any unnecessary information about yourself during the link (for example, where you live or the work you do).
- **Don't** make any unnecessary written notes about the individual or the conversation.
- **Do** destroy all personal information about the individual when the link ends (such as all of their contact details from your email and phone, all written notes you have made).
- Inform us straight away if you think the confidentiality or data protection of an individual has been breached, even accidentally. The only justification for breaching confidentiality is reporting a safeguarding concern to the charity. See **safeguarding** (page 20).

What we ask individuals to do with your personal information

When we link you with an individual, we tell them your first name and contact details to get in touch (phone number and/or email address). We tell them a little about you and why we think you are a good link. We also confirm your first name and contact details in an email.

When they are in contact with you, they are likely to have the following information about you (in addition to your contact details above).

- If they contact you by phone, any messages/texts.
- If they contact you by email, any information you share by email.
- Any information that you have shared with them during the link (this may be verbal or written, depending on how they contact you).

We ask that individuals do the following.

- **Don't** share their Buddy's details or details of the link with anyone outside of the Buddy Service.
- **Don't** share any unnecessary information about themselves during the link (for example, where they live or the work they do).
- **Don't** make any unnecessary written notes about the Buddy (although they may want to make notes about the things you've spoken about. For example, the details of any organisations you've signposted to, or questions they might want to ask their doctors).
- **Do** destroy all personal information about their Buddy when the link has ended (such as all of their Buddy's contact details from their email and phone).

Questions about confidentiality

What are the boundaries of confidentiality within the Buddy Service?

Buddy Service confidentiality applies between the individual, the Buddy and Lymphoma Action (primarily through the Information and Support Services team).

In practice this means that anything that an individual has shared with their Buddy can also be shared by the Buddy with the Information and Support Services team. This is important because it means that you can talk to the team about the contents of a link, and also any issues that you are concerned about and think we need to know about. (See also **When to refer individuals back to Helpline Services** (page 15).

You say the service is confidential but I have seen a story in the press/online about a Buddy. Why is this?

We only share the name, contact details or experiences of our Buddy within Lymphoma Action or as part of making a Buddy link.

However, an exception to this is when a Buddy has *specifically given their consent* for us to share their experiences online or with the media, or as a personal story on our website, in our magazine or in our publications.

We never share a Buddy's details or disclose that they are a Buddy for us, outside of the Buddy Service without their consent.

You might like to use this page to write down any notes from this section of the Handbook.

A large rectangular area with a light pink background and horizontal red lines, intended for writing notes. The lines are evenly spaced and run across the width of the area.

3.

Guidance for supporting individuals

In this section, you will find guidance on:

- Practical issues
- Helpful reminders
- Helpful techniques
- After the link ends



This section focuses on the practical process of taking calls, or responding by email, and the skills used to support individuals. We include some key tips and suggestions for making this a valuable, enjoyable and safe experience for you both.

Having meaningful conversations with individuals is at the heart of the Buddy Service. But it can be very different to having a conversation with family, friends, work colleagues or even people you meet socially or for the first time.

At the start of a conversation it can feel a bit 'unnatural', and you are likely to be sharing very personal information about your experiences with someone you don't know! The conversation can become detailed very quickly, particularly when focusing on a very specific issue. There might be some apprehension on both sides: it can take a lot of courage for an individual to contact you, and you might both feel quite nervous.

The information in this section aims to address some of the issues around how to support an individual you are in a link with, and help you to feel prepared for any conversations.

If you'd like to talk to us about this information before you have a link with an individual, please get in touch. It is important that being a Buddy is a good experience for you, and we want to support you to feel confident in this role.

Practical issues

When and where to have the conversation

Some individuals will get in touch by phone, others by email. The information below may not apply in all situations. By 'conversation' we mean either by email or by phone.

Find a good time to have the conversation

We suggest that individuals make initial contact with you by text or email, to find a convenient time to have a 'proper' conversation. This gives you time to prepare and ensure that you are in the right environment to have the conversation.

It is also important that you don't feel rushed during your conversation, and that the individual doesn't either. Arranging a good time to have the conversation means you can avoid other activities. Of course, things may come up in the moment that mean you don't have much time on the day. In this case, it may be better to rearrange to find a more convenient time for you both.

Find somewhere confidential

It is important to find somewhere you won't be overseen (by email) or overheard (by phone). This is important as you will likely be sharing detailed personal information about your diagnosis and experiences, and the individual may be doing the same. It may be helpful to be at home, in an office or somewhere you know is private. Please avoid having the conversation anywhere public.

Find somewhere free of distractions, interruptions and noise

It is important that you are able to focus on the conversation, so that the individual has your full attention. Finding somewhere where you won't get interrupted is really helpful, and helps you to really focus and not be distracted. And finding somewhere quiet, away from noise, will help you to hear the person and be heard by them. It also helps to find somewhere with a good phone or internet signal!

Helpful reminders

When someone requests a Buddy, it is because they want to share their experience with someone who has 'been there', or they want to hear about someone else's experiences. Often, it is both. The following may help to guide the conversation.

Your experience is your experience *only*

An individual will often want to hear about your experiences of a particular situation, usually because they are going through something similar, or are likely to in the future. However, they may assume that their experience will be the same as yours. So it is important to explain that your experience is what happened to you, and their experience may be different (even if the situation is very similar). Phrases such as "this is just my experience, it might be different for you" can be helpful to use.

What do they want to talk about?

Individuals can feel apprehensive when it comes to actually making contact with you. They might have had a clear idea about what they wanted to talk about, but find it hard to put into words when they contact you. It may be helpful to try and help them to express what it is they would like to focus on. Using phrases such as "is there anything specific you'd like to talk to me about?" or "I understand from the Buddy Service team that you'd really like to talk about..." might help.

Encouraging them to talk first

It may be helpful to ask the individual to tell you a bit about themselves, and what they would like to talk about. Finding out what they know or have experienced so far, can help you understand their situation, and ensure that what you tell them is appropriate and helpful. For example, when talking about treatment, saying something such as "can you tell me about your experiences so far so that I can understand what has been happening for you?" may give you some context and help you to decide what to share.

Offering information bit-by-bit

To help you decide the level of detail to share about your experience, you might want to find out how much the individual wants to know. For example, they might ask you to tell them "all about your treatment" but actually find too much detail overwhelming. It can be helpful to tell them a little, and check if they would like to know more or ask any specific questions. This can help them to feel more in control of the conversation, and gives them the chance to say if they don't want any more detail. It may take them a couple of conversations to feel confident to talk about more challenging issues.

Being a good listener

Listening sounds easy, but it isn't always easy to do. There are different 'levels' of listening, and how much you hear and pick up can vary. We explain more about 'active listening' in the [Helpful techniques](#) section (page 28).

Checking your understanding

Sometimes it's helpful to check that you have understood what an individual has said about their experiences, or what they are asking you. Checking your understanding helps you to avoid making any assumptions about what they have said or asked. Phrases such as "can I check that I have understood correctly..?" can be helpful to use.

Asking questions

Sometimes it is helpful to avoid asking questions if it might interrupt the individual's thoughts or the flow of what they are saying. However, it is important to ask questions if it helps you to understand what they are saying or helps you to frame your answers. It can also help to encourage them to talk. Phrases such as "can you tell me a bit more about that?" or "how was that?" can help to encourage the conversation.

Never give advice

As a Buddy it is important that you **never give advice** to an individual. This means any type of advice including medical advice. The reason for this is that advice may be based on personal opinion or experience, which can be biased and, in the worst case, incorrect or dangerous.

Advice should only be given by someone qualified to give it, and who is appropriately insured to do so. If an individual follows advice given, and this 'goes wrong' or has a negative outcome, the person giving the advice could be blamed and even held legally liable.

When you are speaking to an individual, it may help to remind them that you can only talk about your experiences, and you can't give them advice or tell them what to do. You might like to suggest that they talk to their medical team (or relevant people). Phrases such as "I can't give you advice" or "is there anyone you think you can talk to about this?" may be helpful.

Ending a call

Sometimes it is clear when a call is coming to a natural end, and this can be managed quite comfortably. However, a call might feel like it is 'going around in circles' or isn't winding up. Or you may feel you have given the individual all the help you can, or that you are tired or have run out of time for that day. We often suggest a hour is a maximum length of a call. In these situations, you might want to encourage an ending to the call.

Summarising is a useful technique, and can encourage the individual to recognise that the call is ending. It involves you summarising the things you have talked about during the conversation, such as "we've talked today about your experiences of ... and ..."

Phrases such as "do you feel that we have covered everything that you wanted to today" or "it sounds like there may be more that you'd like to talk about, shall we agree another time to talk?" might be helpful.

After the conversation has ended

Following a conversation, it can be a good idea to give yourself some time to reflect back on it. Naturally, you might think about the individual, and how the conversation was for them.

It is also important to 'check yourself': check if *you are OK* after the conversation. You may have talked about very personal experiences, and it might have brought up memories or emotions for you. You might find it re-awakens some feelings that you were not aware of. Or you may just feel tired or in need of some time to rest.

It is important to recognise how you are feeling and practice some self-care. This might mean giving yourself some time - sitting quietly and thinking through what it has brought up for you.

It can be really helpful to talk through any feelings you are having, to 'process them' and help you to move forwards. You might have a family member or friend that you want to talk to. If you do, please ensure that you focus on your feelings, and **do not share any details of the individual** with them. This is important for the confidentiality of the service.

At Lymphoma Action we use the term 'debriefing'. By this we mean talking to someone about any thoughts and feelings that can come up during the course of a conversation. For example, our Helpline Services team might debrief if they have been emotionally affected by a call they have taken. Debriefing gives the person time to talk about how they are feeling and reflect on why they may be feeling this way.

If you feel that the conversation with the individual has left you with some strong emotions, please consider calling the helpline. The team can support you to talk through any thoughts or emotions that have come up for you, in a safe and confidential environment.

Helpful techniques

Our Buddies come from a variety of backgrounds and have a range of different skills. This section focuses on some skills and techniques you might find helpful when supporting someone through a Buddy link.

The Buddy Service is not a counselling service, and we do not promote it as offering counselling. Although many of the skills and techniques described here are 'counselling-type' skills, and are used in formal counselling situations, we include them here because they may help with your conversations with the individuals you are linked with.

Active listening

Being 'listened to' can be a very empowering feeling. When someone gives you their full attention and shows interest in what you are saying it can be incredibly supportive and insightful.

Active listening is, as the name suggests, an active rather than passive form of listening. In our normal lives, we are listening all the time, to a greater or lesser extent. Active listening is about listening on a deep and concentrated level to what someone is saying, how they are saying it, and what they mean. It often includes also noticing what they are *not saying*.

Active listening involves blocking out what is happening around you and totally focusing on the individual so you can understand what they are expressing, from their point of view.

Using 'open questions' and avoiding interrupting the individual will help them to feel that you are interested in what they are saying, and giving them time to talk.

You might find you don't need to say much at all, but sometimes gentle encouragement might help. This might be making 'mmm' noises so that they know you are still there, or saying things such as "would you like to say more about that?"

Active listening can help you to understand what the individual is going through and what they would like to talk about. It may also indicate how much they want you to share. For example, they might want to talk about side effects of treatment, but you pick up from actively listening that they are actually really scared about what the side effects could be. So this might guide how you talk to them about your experiences.



My type of lymphoma is relatively rare, so I wanted to be there for people with the same type, so they could ask the questions I'd have liked to have asked.

Reflecting

Reflecting is using an individual's exact words and saying it back to them. There are several reasons this can be helpful.

It is a way of showing you are listening to the individual, and *acknowledging* what they have said. It can also help you to check your understanding of what they said.

It can also be a helpful way to encourage the individual to 'reflect on' what they have said. In some cases, they may not be aware of the exact words they have used, but these exact words can be important. Reflecting back allows them to *hear* what they have said, and can encourage them to explore the words and the feelings behind them.

For example, imagine they say "When they said I had lymphoma they were really blunt. It made me really angry. I'm sure that they didn't mean it..." You reflect back to them simply "really angry". They might then say "Did I say angry? Well, not angry as such, but I did feel quite dismissed". Or they might say "Yeah, *really* angry. It was like they didn't think about my feelings at all."

Reflecting is best used sparingly (so that it doesn't sound like you are just repeating everything they say). But it can be very powerful.

Paraphrasing

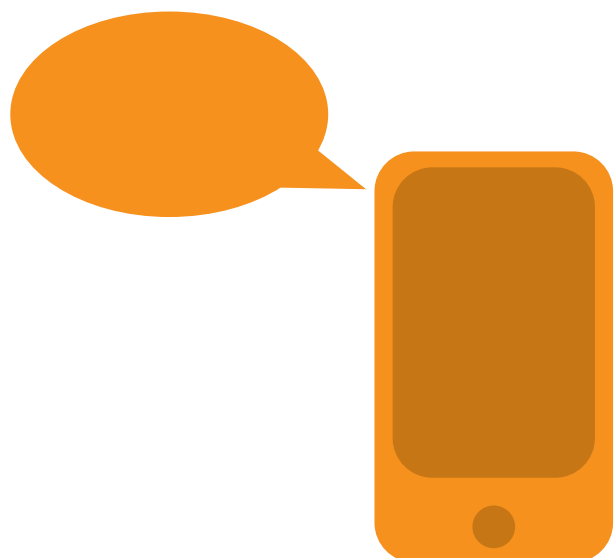
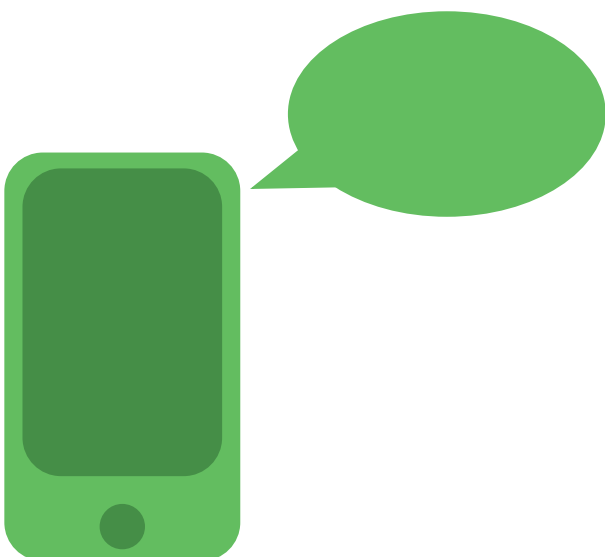
Paraphrasing is similar to reflecting, and can be helpful in the same way: helping you to show you are listening, checking your understanding, and helping the person to think about their own experiences and emotions.

Rather than saying the individual's word back to them exactly, paraphrasing is using your own words to summarise what they have said.

Using the same example, imagine they say "When they said I had lymphoma they were really blunt. It made me really angry. I'm sure that they didn't mean it..."

You paraphrase "so you felt that they didn't think about your feelings at all"

They might then say "Yeah, it was like they didn't think how it might feel for me to hear that."



3. Guidance for supporting individuals

Showing empathy

Empathy is about being able to understand, on a deep and genuine level, another person's experiences and feelings. It is about putting *your* experiences and feelings to one side, and listening without judgement to seek to understand how things are from *their* perspective. It's like 'walking in their shoes'.

You don't have to have had the same experiences or feelings as the person to be able to empathise with them. It is not about telling them what you 'would do', or what they 'should do', but accepting what they are saying with understanding.

'Empathy' is different from 'sympathy'. Sympathy often means 'feeling sorry for' someone without necessarily 'feeling what they are feeling', whereas empathy focuses on really *understanding* how they are feeling.

It can be important and empowering for an individual to feel empathy, and a useful skill to use when you are supporting them.

Techniques such as reflecting and paraphrasing can be a useful way to show empathy. Using carefully worded questions or phrases can be helpful too, such as "how did that feel?" or "what did you think about that?" Rather than saying things like "I know exactly how you are feeling" (which can take the focus off them and onto you), an empathetic response might be "I understand what you are saying."

Being non-judgemental

When you are in a link with an individual, you will have been linked due to your shared experiences. However, we may link you to people who have a very different backgrounds to you, or different beliefs and opinions. There may be times when they say or do something that you don't agree with, that you wouldn't do yourself, or you just might not find common ground which makes it difficult to have the conversation with them. It can be challenging to share your experiences with someone who you don't feel a connection to. Setting aside your own beliefs and judgement, may help you to feel able to share your experiences with them in a useful way.

However, if there is any reason why you feel that you are not able to connect or share with the individual, you may want to just focus on things you do feel comfortable talking about, and gently find a way to end the conversation. Following an interaction like this, please contact a member of the Buddy Service team to talk this through, and so that we can give you some support.

Dealing with emotions

It is quite natural for emotions to come up during the course of the conversation with an individual. They may be feeling lots of different emotions, and they may express this directly, or you may pick up on it yourself.

It may be helpful to acknowledge the emotion directly (for example saying "you sound quite angry about that" or "I can hear that you are upset"). If you feel comfortable to carry on the conversation, please do. However, you may feel that it is appropriate to either suggest to arrange another time to speak again, or to suggest that they might like to call the helpline. Phrases such as "would you like to talk again another time" or "do you think you might like to call the Lymphoma Action helpline?" might be helpful.

Using silences

In everyday conversations we often 'take turns' to talk and share thoughts and experiences. Sometimes when listening to someone else talk it can be tempting to look for them to pause in order to 'take your turn' and start speaking. This is quite normal.

Using silences - or allowing silences to happen - can be a helpful part of active listening. In a conversation where you are specifically supporting another individual, including sharing your own experiences to do this, it can be helpful to find ways of encouraging the other person to continue talking. This is where using silences can be really helpful. Allowing the person to come to the end of what they are saying, and leaving a small gap or silence, might encourage them to say more. It might also give them time to gather their thoughts, without interruption. It is like 'giving them permission' to carry on talking.

Absolute silence can feel a little intimidating sometimes, or the person might wonder if you are 'still there'. And it may feel a little unnatural for you too, to start with. So using gentle encouragement might help, such as 'mmm' noises or asking open questions.

Using open questions

Questions can often be described as either 'closed' or 'open'.

'Closed questions' are questions that lead the person to answer 'yes' or 'no'. They often 'shut down' a conversation and don't leave room for the person to say more. For example, "did you enjoy that book?" leads to a 'yes or no' answer.

'Open questions' are the opposite of closed questions. They avoid the 'yes or no' answer, and encourage the person to give more information. Using the example above, an open question might be "what did you think of that book?"

Using open questions in conversations with the individual you are in a Buddy link with can be really helpful. For example, questions such as "how did you feel when you were diagnosed?" or "what was your experience like?" can encourage them to talk in more detail about their experiences (which might also help you to understand what information to share with them from your own experiences).

Avoiding leading questions

Leading questions are a bit like closed questions, in that they can limit the conversation. They are often based on an assumption, or lead someone to a particular answer. For example, asking "did you feel upset when you were diagnosed" makes an assumption that they probably felt this way (and the person might find it difficult to say if they felt differently, or think they are giving the 'wrong answer'). Asking instead "how did you feel when you were diagnosed" avoids making any assumptions about what they may have felt, and encourages them to answer openly and thoughtfully.

Avoiding SHMOG words!

SHMOG words are 'should', 'have to', 'must', 'ought to' and 'got to'. These words can be very directive, and can be leading or feel quite judgemental. It is often best to avoid using these words where possible. For example "you must speak to your family about..." or "you should try doing..." can appear to be giving advice, or suggest that 'you know best'. See page 27 about not giving advice.

Avoiding SHMOG words and using phrases such as "is there anyone you think might be able to help you with that" or "is there anything you think might be helpful" opens up the conversation, puts the emphasis back on the person, and allows them to think about their response.

3. Guidance for supporting individuals

Setting boundaries

To support Buddies with their links, we have set some boundaries to the service. These are explained to the individual when they request a link, and we describe how the service works.

The boundaries focus on how the individual can contact you, and how often and over what time period. These boundaries aim to reinforce that the service offers short-term support, to discourage them to become reliant on the service or their Buddy, and to discourage 'befriending'. We set these boundaries with advice from some of our current Buddies about what they felt was reasonable.

For example, we suggest individuals can contact their Buddy up to six times or over a period of three months.

These boundaries are designed to support you, so that you are not overwhelmed, but also so that you can remind individuals if you feel it is appropriate to 'reinforce' the boundaries.

However, these are 'guidelines' rather than 'rules' as so you may want to be flexible with how you apply them. If you are in doubt, please contact us to talk this through.

What to share (and what not to share)

When you are in a link with an individual it is important to consider what is helpful to share with them, and what might not be helpful. As the aim of the link is to support the individual, it may be useful to try and think from their perspective. For example, you might have had an experience that could be very worrying or distressing for them to hear about.

Often it will be your personal judgement about how the conversation is going, and what you are picking up from the individual about what they would like to know. If you are unsure about sharing any experience it might be helpful to 'check' with them whether they would like you to talk about it. Reiterating that it is *your experience*, and their experience might be different, is helpful too.

Signposting

During your conversation it may be helpful to signpost the individual to other sources of information and support. This may be organisations, websites or other resources. We have a list of appropriate sources of information and support that you can signpost people to. These are sources that we have checked for appropriateness. Please avoid signposting to any other sources of information.

When signposting on, it is helpful to say that they 'might find them helpful' rather than saying 'this organisation will be able to help' (as we can't promise that an organisation will be considered helpful for that individual. We also use the term 'signposted' rather than 'recommended' or 'directed' so that the individual feels that they have the choice whether to contact the organisation or not (and doesn't feel 'told to'!)



I find it rewarding to speak to people and offer support at their time of need, whether it's just one or two emails or phone calls or a dialogue that continues for a short period.

After the link ends

We hope that Buddy links are valuable to the Buddy, as well as the individual.

After a link has ended, some Buddies find it helpful to reflect back on a link. This might be because it has brought up some memories or emotions for them, or it may be that they would like to look at developing their techniques for having the conversation with the individual. The following is a list of questions you might like to ask yourself, following a call or link. And of course you are welcome at any stage to call us to talk it through.

- Were you able to find a quiet and confidential space to have the conversation? Were there any distractions? Would you do anything differently next time?
- How much time were you able to give to the person? Did it feel about right? If you didn't have enough time or had another appointment, was this a distraction or did you have to cut the conversation short? What would you do differently next time?
- Were you able to fully focus on the conversation? Was there anything that got in the way of you being able to focus? What would you do differently next time?
- How did the conversation go? Was there a good balance between giving your experiences and them sharing theirs?
- Did you use techniques such as active listening or reflecting? How was this? Was anything a challenge or a surprise?
- Were you able to listen without judgement? Were there any times when you felt the need to interrupt? How did you do this and how did they respond?

- Were you able to ask questions? Did your questions help them to reflect?
- In what ways were you able to show you were listening, understanding and empathising? How did that feel? How did they react?
- Did they show any strong emotions (such as anger, worry or distress)? How did you handle this? How did it feel for you?
- Were there any silences on the call? How did that feel? How did the person react?
- Were there any particular issues that you found difficult to talk about? Were you able to share with them?
- Did anything you talked about bring up any issues for you? We would encourage you to call us and discuss anything that the conversation has brought up for you.
- Is there anything you feel went particularly well or you are particularly proud of during the conversation?
- Is there anything that you are concerned about following the conversation? (If so, please call us to talk this through.)

Recording your activity

So that we can recognise the contribution of our Buddies and celebrate the impact of volunteering across the UK, we ask you to log your volunteering hours (how much time you have given to a link).

We have an easy online form that we ask you to fill out after each link via our website here:

lymphoma-action.org.uk/buddy-activity-log

Commonly asked questions

The person I am linked with keeps contacting me/wants to carry on the link longer than usual/longer than I want to. What do I do?

When an individual contacts us about having a Buddy link, we explain what the service does and does not offer. We explain that the link is short-term, and we often suggest that it is up to six times or over a period of three months. We try to not be too prescriptive about this (as each situation is different), but for the majority of individuals this is a suitable length of time to contact the Buddy and get what they need from the service. We also remind them of the terms of the service when we confirm the link with them by email.

Occasionally, an individual may want to keep in contact with a Buddy beyond this time frame. There may be situations where you feel it is appropriate to extend this, *but only with your agreement*.

Where an individual asks to, or is insistent on, continuing the contact beyond what you feel is appropriate, useful or want to offer, you may want to refer them back to the Buddy Service team, giving the helpline contact details. If the person seems reluctant to do this, you can contact us and we will contact them, and ask them to not contact you again. Alternatively, you can talk through with us ways to reinforce the boundaries yourself if you prefer.

I feel a real connection with the person I am in contact with. Can I carry on contacting them?


The boundaries of the Buddy Service are clear that the relationship between a Buddy and the individual is short-term only, and is not a friendship service. We can only support you whilst you are in contact with an individual under the terms of the Buddy Service.

However, there may be individuals that you are linked with, with whom you have a particular connection, or you feel a friendship developing with, and that can be quite natural. In this situation, if you would like to continue to be in contact with the individual, you must be clear that this is not part of the Buddy Service.

Will I get any feedback from the individual I have linked with?

A couple of months after we make a link, we contact the individual to request feedback. This is so that we can see if the service was useful to them, and whether it made a difference to them (we refer to this as 'impact').

We ask individuals if there is anything that they would like to share about their Buddy link, and whether we can pass this on to the Buddy. Where we are given permission to share feedback with you, we will get in contact with you.

You can see a copy of our Feedback form in the [Appendices](#)  (page 56).



Being a buddy meets a growing need and provides the satisfaction of giving reassurance and comfort to others who may well be lost and not know how best to face the future.

You might like to use this page to write down any notes or reflections on a link you've had.

A large rectangular area with a light green background and a dark green border, containing 20 horizontal lines for writing.

4.

Key resources summary



Welcome

In this section, you will find guidance on:

- A list of key volunteering resources, guidance and documents
- Details of where to find them







Key resources summary

This section provides a list of the current key resources and information available to you as a volunteer.







As we regularly review, update and add to our resources list, we will communicate any changes or new resources when they become available. You can access the up-to-date list of available resources on our dedicated volunteer resources webpage: **lymphoma-action.org.uk/vr**

In case of difficulty, or if you would like a paper copy, they are also available from the Volunteering Development Manager.







Your volunteer role

-  About our closed Facebook group for Buddies
-  Buddy role description and specification
-  Our expectations of Buddies
-  Outline of the Buddy Service
-  Terms of service
-  Volunteer activity log



Policies and procedures

-  Confidentiality and data protection
-  Expenses and claim form
-  Equality & diversity
-  Health, safety & wellbeing
-  Lone volunteering
-  Safeguarding

Resources

-  Incident report form for volunteers
-  Recording your volunteer activity
-  Sharing information responsibly
-  Social media guidance for volunteers
-  Symptoms poster and postcard
-  Useful reading and video list about lymphoma and Lymphoma Action

Other

-  Volunteering Strategy 2019 – 2022
-  Lymphoma Action Strategy 2020 – 2025

5.

Appendices



This section includes some of the key background documents that support the service. It also includes some examples of how we report on the impact of the service, and how we communicate with you.

1. Role description and specification

This is the current role description and specification that we use when we recruit new Buddies onto the service.

2. What the service offers (and doesn't offer)

This is a 'snapshot' of what the Buddy Service offers and, importantly, what it doesn't offer. This information is included on the Buddy Service page on the website:

lymphoma-action.org.uk/buddy-service

3. Terms of service

This is an outline of what the service offers, and is designed for people who are considering requesting a Buddy. It also includes what we expect from individuals when they use the service. We usually talk through this with individuals when they request a Buddy, and also send them a link to it when we confirm a Buddy link.

This is also a useful document for when Buddies are in a link with an individual, should they need to remind the individual of the boundaries of the service.

4. Our expectations of Buddies

This is a description of what we expect from our Buddies. It is a bit like a 'code of conduct', and acts a snapshot of what our Buddies do. It is also useful to reassure individuals about the service and what *they* can expect from a Buddy.

5. Request a buddy link

This outlines the information we ask from an individual in order to see if we are able to match them with a Buddy.

6. Buddy updated experiences form

When a new Buddy joins the service, we ask them to complete an 'experiences form' (online). This asks about their lymphoma and their experiences, so that we can use the information to see if they would be a suitable Buddy for an individual. Every couple of years, we ask Buddies to complete an updated experiences form – to ensure that we have correct and up-to-date information from them. This is an outline of the information we ask from our Buddies.

7. Our Buddy Service – tell us what you think (feedback form)

This is a copy of the feedback form that we ask individuals to complete after their Buddy link.

8. Incident form

In the event that something happens during a Buddy link that you are concerned about, and think we should know about, you can use an incident form to report this to us. Examples of when you might do this include the following.

- You are worried about an individual's physical health and you have suggested to them that they call their doctor or healthcare team.
- You feel that an individual is abusing the service and that we should know about it so that we can act on this information.
- You are concerned about an individual's psychological health or emotional wellbeing, and you want to report this to us so that we can contact them if necessary.

Finding these resources

Some of these documents can be found in the Buddy Service section of the website:

lymphoma-action.org.uk/buddy-service

Some can be found on our dedicated volunteer resources webpage: lymphoma-action.org.uk/vr
All are available from the Buddy Service team.

Buddy Service Buddy – role description and specification

Responsible to: Education & Support Services Manager / Volunteering Development Manager

Location: home-based/ National

Time Commitment: variable. Expect periods with no links, and during links we suggest contact around six times or over a period of three months. Each contact is likely to be up to an hour.

About Lymphoma Action

With the help of our passionate volunteers we're ensuring that no one has to face their lymphoma alone. Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer and the most common cancer in young people aged 15-24. We've been providing in-depth, expert information and support for over 30 years, helping thousands of people affected by lymphoma.

How this role makes a difference

Our Buddy Service offers people affected by lymphoma the opportunity to talk to someone with similar experiences. Individuals are linked to a Buddy with closely-matched experiences, to share their experiences. Buddies offer this support on a time-limited basis, via phone or email. The service is not a befriending service, counselling or a long-term support.

The Buddy Service aims to:

- offer peer-support on a one-to-one basis by phone or email;
- put individuals in touch with a buddy with closely-matched experiences; and
- offer a short-term opportunity to share experiences with someone who 'understands what they are going through'.

As a Buddy you will use your personal experience of lymphoma to support others affected by lymphoma to feel understood, less isolated, and more able to cope with living with their lymphoma. Our Buddies include people with lymphoma as well as family members and carers.

What's involved?

- Delivering short-term support by phone or email to an individual. This might be individuals with lymphoma, or a family member or carer (depending on your situation and experiences).
- Using your own experiences of lymphoma to empathise with and support individuals who are in similar situations to your own, or who are likely to be going through something similar (for example, particular treatment regimens).
- Using interpersonal skills to sensitively share your experiences, whilst observing boundaries of the role and signposting back to Lymphoma Action as appropriate.
- Volunteering within Lymphoma Action guidelines, policies, procedures and record-keeping.

What skills and experience you'll need

- A personal experience of lymphoma is required. You may have, or have had, lymphoma yourself, or you may be a family member or carer of someone who has or had lymphoma. You will have come to terms with your own diagnosis, or that of the person close to you, and be able to support others sensitively.
- You'll feel comfortable and able to talk about your experiences of lymphoma and the emotions around this, and be able to support others through their own experiences.
- You'll be engaging, empathetic and non-judgemental, and able to communicate well with a range of people, ages and backgrounds.
- You will be able to understand and adhere to the boundaries of the role, including not offering medical or other advice, not offering 'counselling', not encouraging dependency or an on-going relationship.
- Experience of skills used to support people, such as active listening skills, empowerment and emotional support are an advantage.
- You will be able to offer contact by email and phone, and have access to a quiet and confidential space to offer this contact.
- You will be over 18 years of age.
- You will be at least 12 months on from completing treatment or starting on active monitoring.

Training and support you will be given

- Induction to Lymphoma Action.
- Specific training to deliver the Buddy role (delivered as a one-day training workshop).
- Ongoing support from a designated Lymphoma Action team, and opportunities to debrief with the team following contacts.
- Additional support from the Volunteering Development Manager.
- News and updates about volunteering for Lymphoma Action.

What you will get out of volunteering with us

- You'll make a positive impact in supporting people affected by lymphoma.
- You'll be part of our volunteering community who are at the heart of our work.
- You'll develop a deeper understanding of lymphoma and the work of a national charity.
- You'll bring your own expertise and interests to the role.
- You'll improve your own wellbeing by connecting with others.

Buddy Service

What the service offers (and doesn't offer)

Our Buddy Service aims to connect you with a Buddy who has a personal experience of lymphoma so that you can share experiences. The following explains what the service offers (and doesn't offer) so that you can decide whether the service is right for you. Before you apply for a Buddy, you will need to read and agree to our Buddy Service terms of service (which is part of our 'request a Buddy form').

Our Buddy Service offers support and an opportunity to speak to someone with lived experience of lymphoma. Our Buddies may have the same type of lymphoma as you, and often will have had treatment similar to the treatment you have had, or may be about to have. They may also have similar lifestyle experiences as you. Some of our Buddies are family members or carers, and so we offer this service to you if you are a family member or carer of someone with lymphoma. Our Buddies offer you empathy and understanding, sharing experiences and a listening ear.

What the Buddy Service offers

- Buddies offer peer support and an opportunity to speak to someone who has been through a closely-matched experience to you, to share your experiences with.
- We match you based on experiences (not geographically - Buddies come from all over the country).
- It is a short-term arrangement. Although it can vary from one person to another depending on the situation, we usually suggest that you can contact your Buddy up to six times or over a period of three months.
- You can contact your Buddy by email or phone, on a one-to-one basis.
- All of our Buddies have been through a recruitment process, including giving references. They are also trained so you can feel confident that they'll support you in the best way they can.
- The service is for you if you are aged 18 or over, living in the UK and have either been diagnosed with lymphoma or know someone who has (for example, you are a family member or carer for someone with lymphoma).
- We share only limited details about you with your potential Buddy - your name, your condition and what you'd like to talk about. And we'll tell you a little about them too, and why we've matched you with them.
- We do our best to find a suitable Buddy for you, however this isn't always possible.
- It can take a few weeks to find a suitable match for you.

What the Buddy Service doesn't offer

- The service is not a long-term arrangement or on-going relationship. It is not a befriending or 'friendship' service.
- The service is not a counselling or therapy service, and our buddies are not counsellors.
- Our buddies are not able to give you advice. They are not medically trained and cannot give medical advice.
We suggest that you speak to your own medical team about any medical questions you have.
- The service is not available to residents outside of the UK or anyone under the age of 18.
- Buddies are not able to meet you in person, or contact you outside of the Buddy Service.

How to contact the Buddy Service

To get in touch with the Buddy Service, please call the helpline on (freephone) 0808 808 5555, or email information@lymphoma-action.org.uk

Whether you use the Buddy Service or not, you can also use our Helpline Services

- 📞 0808 808 5555 (10am - 3pm, Monday - Friday)
- ✉ information@lymphoma-action.org.uk
- 💻 www.lymphoma-action.org.uk and look for the Live Chat button

Appendix 3

Buddy Service

Terms of service

Welcome to our Buddy Service. Here we explain what you can expect from our Buddy Service. We also explain what we ask from you, so that we can offer you the best service and a good experience of having contact with a Buddy.

About the service

- Our Buddy Service offers support and an opportunity to speak to someone with lived experience of lymphoma. Our buddies may have the same type of lymphoma as you, and often will have had treatment similar to the treatment you have had, or may be about to have. They may also have similar lifestyle experiences as you. Some of our Buddies are family members or carers, and so we offer this service to you if you are a family member or carer of someone with lymphoma. Buddies offer empathy and understanding, sharing experiences and a listening ear.
- The service is not a counselling, therapy, befriending or 'friendship' scheme.
- The service offers short-term contact with a Buddy (usually six times or over a period of three months).
- Any ongoing or long-term contact, or any friendships that develop, are not part of the Buddy Service and would not be recognised by us as part of the service.
- Our Buddies are not counsellors, medically trained or able to give advice. They can talk to you about their experiences of lymphoma and how it affects them, and about your experiences. Please remember that your buddy's experiences may not exactly match your own and they are simply sharing their experiences with you.

If we find a Buddy for you

- If we find a Buddy for you, please contact them within two weeks, even if it's just to arrange a time to talk. Some people find it helpful to contact their Buddy by email or text first to arrange a good time to talk.
- **If you change your mind about having a Buddy that's fine.** We just ask that you let us know within two weeks so that we can let them know that they won't hear from you.
- **The service offers short-term contact.** Although it can vary from person to person, depending on the situation, we usually suggest that you can contact your Buddy up to six times or over a period of three months. However, we understand that everyone's situation is different and sometimes longer-term contact might be helpful. You can talk directly to your Buddy about whether this would be possible, and they might talk to us about whether they are able to offer this. If your Buddy is not able to offer this, you can talk to us about having another link.
- **Our Buddies cannot give you advice.** Any information that your Buddy shares about their own experience should not be taken as advice. We recommend that you discuss any concerns about your condition and its treatment with your own medical team.

Confidentiality

- We only share limited information about you with your Buddy. We give them your first name, and an overview of your diagnosis and what you would like to speak to them about. This is to check that the Buddy feels they have the right experiences to share with you. Similarly, we will tell you your Buddy's first name and an overview of *their* experience so that you can see why we are suggesting them as a Buddy for you. We will also give you their contact details (phone number and/or email address, depending on how you want to contact them).
- To maintain your confidentiality and that of your Buddy, *you must not keep or share any information about your Buddy with anyone outside of the Buddy Service.*
There may be situations where you want to share information about your Buddy, such as at a lymphoma support group or event. *You must not share any personal details about your Buddy.*
Any information that you have, for example, your Buddy's contact details, *must be destroyed after the link has ended* (for example, by shredding or deleting the information).
- Our Buddy Service does not offer face-to-face support. However, it may be possible that you meet your Buddy by accident, for example, at a Lymphoma Action event or Support Group. If this happens, please do not discuss your link with your Buddy in this environment. This is to ensure the confidentiality of the service.
- As part of your link, your Buddy may signpost you on to other, reputable organisations, appropriate to your situation. It is important to recognise that we cannot *recommend* these organisations, and it is your choice whether you follow up these signposts or not.

Looking after yourself

- We understand that there may be times when you feel particularly distressed or emotional, and this is completely understandable. We ask that you don't contact your Buddy when you are feeling this way, as they are not trained counsellors, and are a Buddy in a voluntary capacity. Instead, please call our helpline on (freephone) 0808 808 5555 (10am to 3pm, Monday to Friday). The helpline can offer you time and space to talk in a confidential environment, and can signpost you on to other sources of support if that is helpful. Outside of these times, you may like to call the Samaritans on 116123.
- In some cases, your Buddy might suggest that you contact our helpline, perhaps instead of using the Buddy Service. For example, this might be if:
 - you are distressed or they are worried about your emotional wellbeing;
 - you are concerned about medical issue (or they may suggest that you contact your doctor or specialist);
 - you appear to be dependent on your Buddy or the service, or the service is not able to offer you what you need;
 - your Buddy does not feel that the link is appropriate, or they become unable to make a link with you; or
 - you make contact with them again after the link has ended.
- Sometimes, talking with your Buddy about their experience could bring up emotions and feelings for you. If you would like to talk this through, please contact the helpline for additional support.

After your link has ended

- Our Buddy Service offers short-term contact. Usually this is around six times or over a period of three months. After this time, the link is ended.
- If you want to contact your Buddy again *after* the link has ended, or your experience has changed since you spoke to your Buddy, please contact the Buddy Service again (do not contact your Buddy directly). This is because your Buddy may no longer be available, they may be linked to another individual, or they may no longer be the most suitable link for your experience. We can try and find you a new, suitable, Buddy.
- Around six weeks after we have made a Buddy link for you, one of our volunteers will contact you to ask for feedback on the service. Your feedback is important as it helps us to understand how the service is working and how we can best support you. You can give feedback over the phone, or they can send you a link to a survey online. (Please note: these volunteers are independent of the Buddy Service and will only contact you about your experience of the service itself. If you would like to talk about your condition or experiences, please call the helpline.)

Please remember that you are welcome to use any of Lymphoma Action's services, such as our Helpline Services or Support Groups, whether you are currently linked with a Buddy, if you change your mind about having a Buddy, or your link has ended.

Please note: we require you to read and agree to this terms of service before we can make a Buddy link for you.

Disclaimer

Lymphoma Action cannot be held responsible for any actions that you take as a result of using the Buddy Service, or for any actions that you take that contravene these terms.

How to contact the Buddy Service

To get in touch with the Buddy Service, please call the helpline on (freephone) 0808 808 5555, or email information@lymphoma-action.org.uk

Whether you use the Buddy Service or not, you can also use our Helpline Services

 0808 808 5555 (10am - 3pm, Monday - Friday)

 information@lymphoma-action.org.uk

 www.lymphoma-action.org.uk and look for the Live Chat button



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Lymphoma Action, Unit 3, Bell Business Park, Smeaton Close, Aylesbury, Bucks HP19 8JR
General enquiries 01296 619400

Registered company in England and Wales (03518755).

Registered charity in England and Wales (1068395) and Scotland (SCO45850).

Buddy Service

Our expectations of Buddies

Thank you for being a Lymphoma Action Buddy. Here we explain what we expect from our Buddies to ensure we offer individuals a safe and consistent experience when they use the service. You may like to read this alongside the Buddy Service Terms of Service, which explains to individuals who may want to use the service what the service offers, and what we expect from them (lymphoma-action.org.uk/Buddy-Service).

What the Buddy Service offers

- The service is not a counselling, therapy, befriending or 'friendship' scheme. We suggest to individuals that they can contact you six times or over a period of three months. This is a guideline and we appreciate that the number of times they contact you will vary depending on their situation, and sometimes slightly more contact may be helpful. The individual can discuss this directly with you, and you can talk to us about this if you would like to. But you are under no obligation to extend this. We offer this guidance so that you are not over-whelmed, or if you feel that gently giving some boundaries might be helpful for you or the individual. However, if long-term contact continues (for example, for a year or more) this is not part of the Buddy Service and would not be recognised by us as an active Buddy link. There may be instances where individuals may need to be gently reminded of this.
- Please make it clear to the individual that the experiences you share are your own (recognising that other people will have other experiences). We explain this to individual's but it may be helpful to remind them. It can be helpful to explain that your experience may be different to theirs, and we only expect you to share your experiences.
- As a Buddy you are required to **not give advice** (including medical advice). Please be aware that if an individual were to act on advice that you give, there could be a negative impact on the individual, on you and on Lymphoma Action. Therefore, **the Buddy Service does not give advice**. (If you give advice you will be held liable for this and Lymphoma Action will not take any responsibility for this as we have asked you to not give advice).

When you are in contact with an individual

- When we make a link, we give the individual your contact details, and ask them to contact you within two weeks either to talk, or to arrange a time to talk. We don't give you their contact details, and we don't ask you to make contact with them. This is so that they can decide whether to make contact or not. Some people change their minds about making contact, and we ask them to let us know if they have changed their mind (and we will let you know if they do this). If the individual has contacted you and left a message, you can then contact them back (as they have already made that first contact with you).
- Please make sure that you are in a confidential and quiet place to take calls, and away from disturbances, so that you can focus on the support you are giving, and where your conversation cannot be overheard.
- We have a list of third party organisations that you can signpost individuals to (that we have checked for suitability) and there is a list of 'useful organisations' on our website at lymphoma-action.org.uk. If you signpost to an organisation please make it clear that it is not a *recommendation*, and that we cannot guarantee that it will be helpful. Please don't signpost to organisations not on the list (as we have not checked them).
- Please refer individuals back to our helpline services when appropriate.

Please ensure that you refer individuals back in the following circumstances:

- they appear to be suicidal;
- you feel that they may be dependent on you or on the service;
- you feel that they are misusing or abusing the service (for example, they repeatedly contact you outside of the service boundaries, or they don't appear to be using the service for its intended use);
- you don't feel the link is appropriate, or you are not able to fulfil the link request for any reason;
- they contact you after the link has ended or after a long period of time;
- you have any concerns about their medical or emotional wellbeing (or suggest they call their medical team);
- they disclose any information that you are concerned is, or could be, a safeguarding issue; or
- there is any other reason why you are concerned.

If we have any concerns about an individual who requests a link, we will usually not make a link but rather try and signpost them to an appropriate service. Please see our policies on safeguarding for more information. These can be found at: lymphoma-action.org.uk/vr/Buddy

After your link

- You may like to contact us after having a link to talk through the link or discuss any issues or concerns that have come up for you during this link. This is an important part of looking after your own wellbeing.

Requirements around confidentiality

- All Buddies are required to sign a confidentiality agreement when they become a Buddy, and agree to adhere by this agreement. This is to protect them, the individual, and the charity.
- When you have a link to an individual, please ensure that you:
 - do not share the individual's personal details or details of the link with anyone outside of the Buddy Service;
 - avoid sharing any unnecessary information about yourself during the link (for example, where you live or the work you do); and
 - destroy any personal information about the individual when the link has ended (for example, deleting emails or phone numbers).

You can find more information about this topic in our data protection policy and confidentiality agreement on the volunteering section of our website at: lymphoma-action.org.uk/vr/Buddy

- In the unlikely event that you meet the individual you have linked to by accident (for example, at a Lymphoma Action event or Support Group), we suggest that you do not acknowledge knowing them from the Buddy Service, unless they initiate this. In this instance, please do not discuss the details of the link in this environment as it would affect the confidentiality of the service.

Keeping us up to date

- Please keep us up to date with your contact details and any relevant changes in your health circumstances. This is to support your wellbeing and ensure that we give you time to focus on your own needs outside of the service (for example, if you are having treatment for your lymphoma).

We ask that you let us know the following:

- if there are any changes to your contact details (we use these to keep in touch and to pass on to individuals);
- if you have had any changes to your lymphoma (for example, if you are having treatment we would not make any links with you during your treatment and for a few months afterwards);
- if there are any other reasons why you would not be able to take on a link, for example, you are busy or feel unable to help (so that we don't approach you about links if you are taking some time away from the service).

In some instances there may be changes to your lymphoma that it would be helpful to tell us about, as new experiences may mean that we are able to make links to you *because* of these new experiences.

Remember: you are welcome to use any of Lymphoma Action's services at any time, for your own personal needs. This includes Helpline Services and the Buddy Service (if you would like to be linked to a buddy).

Disclaimer

Lymphoma Action cannot be held responsible for any actions that you take as a Buddy, or for any actions that individuals using the service take following their link with you, if you breach the terms of this code of conduct.

How to contact the Buddy Service

To get in touch with the Buddy Service, please call the helpline on (freephone) 0808 808 5555, or email information@lymphoma-action.org.uk

Whether you use the Buddy Service or not, you can also use our Helpline Services

 0808 808 5555 (10am - 3pm, Monday - Friday)

 information@lymphoma-action.org.uk

 www.lymphoma-action.org.uk and look for the Live Chat button



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Buddy service Request a Buddy link

Welcome to our Buddy service. If you would like to be linked to one of our buddies, please complete this form, in as much detail as you can, and return it to us. We will try and match you as closely as possible to one of our buddies, so that you can share experiences. Once we have received this form, we will call you to talk through your needs and expectations, and tell you a bit about the service and what happens next.

Your contact details

Name _____

Home number _____ Mobile number _____

Can we leave a message with someone else or on your answer phone? Yes No

Note: if we ring you, our phone number shows as 'withheld'.

Your email address _____

We will send you a link to our Terms of Service and confirm the details of your buddy link by email.

Your postal address including postcode _____

We will use the information you give us below to try and find you an appropriate buddy.

We'll also pass on any relevant information to your buddy.

About your lymphoma

Are you: an individual with lymphoma a partner/carer a relative/friend

What specific type of lymphoma do you have? _____

What stage is your lymphoma (if you know)? _____

When were you diagnosed? _____

What treatment have you had, if any (such as specific chemotherapy regimens or radiotherapy)?

What would you like to talk to a buddy about (so we can find a suitable match for you)?

- | | | |
|---|---|---|
| <input type="checkbox"/> Mood (anxiety/depression) | <input type="checkbox"/> Fatigue | <input type="checkbox"/> Nausea/vomiting |
| <input type="checkbox"/> Bereavement | <input type="checkbox"/> Fertility | <input type="checkbox"/> Neuropathy |
| <input type="checkbox"/> Bowel changes | <input type="checkbox"/> Financial issues | <input type="checkbox"/> Neutropenia |
| <input type="checkbox"/> Cognitive/memory issues | <input type="checkbox"/> Hair loss | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Coping with family/friends | <input type="checkbox"/> Insurance | <input type="checkbox"/> Pregnancy |
| <input type="checkbox"/> Coping with remission | <input type="checkbox"/> Joint problems | <input type="checkbox"/> Splenectomy |
| <input type="checkbox"/> Diet/nutrition | <input type="checkbox"/> Side effects - early | <input type="checkbox"/> Watch and wait (active monitoring) |
| <input type="checkbox"/> Treatment | <input type="checkbox"/> Side effects - late | |

Is there anything else, not listed on page one, that you'd like to talk to a buddy about?

Your buddy preferences

How would you like to contact a buddy? Phone Email Either

Are you happy to talk to a buddy of a different gender? Yes No

If 'no', please tell us your gender Male Female

Are you happy to talk to a buddy of a different age? Yes No

If 'no', please tell us your age _____

Do you have any communication needs/preferences that you would like us to bear in mind, and pass on to a potential buddy? _____

How did you hear about the Buddy service? _____

Mailing preferences

We'd love to keep you updated with the latest lymphoma news, events, support services, campaigns and ways you can get involved – including through our Lymphoma Matters magazine. Note: as we are a UK charity we can only send our magazine by post to the UK.

I am happy for Lymphoma Action to contact me: Post Email Both None

Thank you for requesting a buddy

Please return this form in the FREEPOST envelope provided or email to information@lymphoma-action.org.uk

For office use only

Terms of service: verbally notified confirmed read email notification sent

Buddy user ID number _____

Buddy linked with - name _____ ID number _____

Best times to contact buddy _____

Date request received _____ Date link made _____

Follow up date _____

Buddy updated experiences form

Thank you for being a Lymphoma Action Buddy!

When making a link between an individual and a Buddy, we try and find a close match of experiences. The more information we have about you - as a Buddy - the better able we will be to make these close matches. For many of our Buddies, their initial application to the service was many years ago, and so we are updating the details and experiences of all of our Buddies so that we have accurate, up-to-date and relevant details, and to make sure that we can compare Buddy experiences to make a link.

Your contact details

Name _____ Known as _____

Home number _____ Mobile number _____

Can we leave a message with someone else or on your answer phone? Yes No

Note: if we ring you, our phone number shows as 'withheld'.

Your email address _____

You might like to create a new, free email address to give out to buddy links (so that your personal details are not obvious from your email address). For example, an email such as 'BuddyJohn@gmail.com'

Your postal address including postcode _____

Your date of birth (individuals may want to link with a Buddy of a similar age) _____ / _____ / _____

Your gender (individuals may want to link with a Buddy of the same gender) _____

We will use the information you give us below when making a link to an individual. Please be aware that we will pass on some of your details and experiences to the individual, to explain why we think you'd be a good link for them. (However, we never give your surname or home address details.)

Please do not tell us anything on the following pages that you would not like to be passed on.

About your lymphoma

Is/was your lymphoma Hodgkin High-grade non-Hodgkin Low-grade non-Hodgkin

What specific type of lymphoma do/did you have? _____

What stage is/was your lymphoma (if you know)? _____

When were you diagnosed? _____ What age were you? _____

Which areas of your body were/are affected? _____

Has your lymphoma transformed (changed in type)? Yes No

If so, when did it transform? _____

What type was it before and after transforming? _____

About your treatment

Please tell us about your treatment (so we can match you with people who have the same treatment).

Active monitoring (or 'watch and wait')

Have you been on 'active monitoring'? Yes No

If so, when and how long for? _____

Chemotherapy

Have you had chemotherapy? Yes No

If so, when and what regimen(s) did you have? _____

Antibody therapy (for example, rituximab and obinutuzumab)

Have you had antibody therapy? Yes No

If so, when and what antibody did you have? _____

Radiotherapy

Have you had radiotherapy? Yes No

If so, when, what type and where on the body did you have it? _____

Stem cell (bone marrow) transplants

Have you had a stem cell harvest? Yes No

Have you had a stem cell transplant? Yes No

If so, was it an 'auto' stem cell (your own cells) and/or 'allo' stem cell (from a donor)?

Relapses

Has your condition ever relapsed? Yes No

If so, when and what happened _____

Clinical trials

Have you taken part in a clinical trial? Yes No

If so, when and what trial(s)? _____

What side effects, if any, have you experienced from treatment?

- Fatigue Nausea/vomiting Cognitive/memory issues Hair loss
 Sore mouth Bowel changes Neutropenia (low white blood cells)
 Thrombocytopenia (low platelets) Anaemia (low haemoglobin or red blood cells)
 Peripheral neuropathy (nerve damage)
 Other side effects _____

Have you experienced any late effects (health problems that may develop months or years after treatment for lymphoma)?

- | | | |
|---|--|--|
| <input type="checkbox"/> Second cancers | <input type="checkbox"/> Heart disease | <input type="checkbox"/> Lung problems |
| <input type="checkbox"/> Hormone problems | <input type="checkbox"/> Other late effects: _____ | |

Do you have any other experience you feel would be relevant to share?

- | | | |
|--|--|--|
| <input type="checkbox"/> Bereavement | <input type="checkbox"/> Complementary therapies | <input type="checkbox"/> Coping with remission |
| <input type="checkbox"/> Counselling | <input type="checkbox"/> Diet/ nutrition | <input type="checkbox"/> Family relationships |
| <input type="checkbox"/> Fertility | <input type="checkbox"/> Finances/benefits | <input type="checkbox"/> Joint problems |
| <input type="checkbox"/> Pregnancy | <input type="checkbox"/> Mood (anxiety/depression) | <input type="checkbox"/> Other people's feelings |
| <input type="checkbox"/> Second opinions | <input type="checkbox"/> Splenectomy | <input type="checkbox"/> Work |

Other: _____

Do you have children?

- | | | |
|-----------------------------|--|---|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes - before my diagnosis | <input type="checkbox"/> Yes - since my diagnosis |
|-----------------------------|--|---|

Please complete the following questions in as much detail as you can. Your experiences, good and bad, are the basis of how we make a link. The more we know about you, the more likely we are to make a good match. Please continue on a separate sheet if you like.

What symptoms did you experience leading up to your diagnosis, and how did you feel at the time?

Did you have any side effects from your treatment, or any symptoms on active monitoring (watch & wait)? How did you feel at the time?

(If you ticked any side effects on page 2, or experiences above, please give more details here).

Volunteer Confidentiality & Data Protection Agreement

Under the General Data Protection Regulation (GDPR), Lymphoma Action has a legal responsibility to protect all information given to us by individuals and organisations.

As a Lymphoma Action volunteer (Buddy), it is important that you understand and comply with the charity's data protection and confidentiality policies and procedures. This includes following all instructions about the processing and security of personal data.

Confidential information should not be discussed outside of the charity and must not be used for your own purposes. Your duty of confidentiality continues after your volunteer involvement with the charity has ended.

As set out in the expectations above, we commit to providing you with the information and training to carry out your role, which includes confidentiality and data protection and ask you to follow all processes and instructions given.

You can read our confidentiality policy at: lymphoma-action.org.uk/vr

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

Your name:

Date:

Signature:

Please note: all Lymphoma Action volunteers are required to agree to and sign this agreement.

Therefore all Buddies are required to sign this agreement in order to continue to be a Buddy for Lymphoma Action.

Thank you!

Please return this form in the FREEPOST envelope provided or email to information@lymphoma-action.org.uk

For office use only

Buddy ID number

Date received



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Lymphoma Action, Unit 3, Bell Business Park, Smeaton Close, Aylesbury, Bucks HP19 8JR

General enquiries 01296 619400

Registered company in England and Wales (03518755).

Registered charity in England and Wales (1068395) and Scotland (SCO45850).

Our Buddy service - tell us what you think

Thank you for using our Buddy service. To help us continuously review and improve our service, we would like to know your views and experiences about using our Buddy service. You can share your feedback anonymously if you like, although if you have any specific feedback you'd like us to share with your buddy, or anything you would like us to respond to, we would need your name in order to do this.

Did you make contact with your buddy?

- Yes - once Yes - more than once Yes - and I plan to again in the future
 No Not yet - but I plan to

If you decided not to make contact, please tell us why

Did you find the contact with your buddy helpful?

- Yes - very Yes - a little No

Please tell us a bit more about your answer

Before being in contact with your buddy, how did you feel? (Please tick all that apply.)

- | | |
|---|---|
| <input type="checkbox"/> I didn't know much about my condition | <input type="checkbox"/> I didn't feel supported |
| <input type="checkbox"/> I didn't feel confident | <input type="checkbox"/> I felt isolated |
| <input type="checkbox"/> I felt vulnerable | <input type="checkbox"/> I felt fearful/worried |
| <input type="checkbox"/> I felt a lack of control in my life/my condition | <input type="checkbox"/> I wanted reassurance |
| <input type="checkbox"/> I felt that no one understands what it is like | <input type="checkbox"/> I felt anxious/ agitated |

Other (please explain):

After being in contact with your buddy, how do you feel? (Please tick all that apply.)

- | | | |
|--|--|---|
| <input type="checkbox"/> More informed | <input type="checkbox"/> More supported | <input type="checkbox"/> More confident |
| <input type="checkbox"/> Less isolated | <input type="checkbox"/> Less vulnerable | <input type="checkbox"/> Less fearful/worried |
| <input type="checkbox"/> More empowered/in control | <input type="checkbox"/> More reassured | <input type="checkbox"/> Like someone understands |
| <input type="checkbox"/> Calmer | <input type="checkbox"/> Relieved | |

Please use this space to share any other experiences about the contact with your buddy

When we link someone with a buddy, we take time to try and ensure that we get as close a match as possible, in terms of condition, treatment and experiences. This is so that the link is relevant to you, and you get the most out of it. This can take time, and sometimes means that we can't always find a buddy for someone.

Did you feel that your buddy was a good match for you?

- Yes - very Yes - a little No

Please tell us more about your answer

If we had matched you with a buddy who didn't have the same condition, treatment or experiences, do you think this would have made a difference to you?

- Yes - very Yes - a little Probably not No I'm not sure

Please tell us more about your answer

Would you use the buddy service again in the future?

- Yes Possibly Probably not No

Would you recommend the buddy service to other people?

- Yes Possibly Probably not No

Is there anything else you would like to share with us about using the service?

Sharing and using your feedback

We may like to use any comments you give as quotes in our materials and to promote our services.

Please tell us whether you are happy for us to do this.

- Yes – you can use my comments as quotes No – you can't use my comments as quotes

To support our buddies, we like to share any feedback about their links with them. This is also an opportunity for you to tell us anything you would like us to share with your buddy. So we would like your permission to do this.

- Yes – you can share my comments with my buddy. (Please tell us your and their first names.)

My **first** name is: _____ My buddy's **first** name is: _____

- No – I would like to keep my comments confidential.

Thank you for sharing your experiences with us

Please return this form in the FREEPOST envelope provided



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Lymphoma Action, Unit 3, Bell Business Park, Smeaton Close, Aylesbury, Bucks HP19 8JR
General enquiries 01296 619400

Registered company in England and Wales (03518755).

Registered charity in England and Wales (1068395) and Scotland (SCO45850).

Incident report form

This form can be used to record any 'reportable' incident. This includes incidents of safeguarding, acts of terrorism, suicidal individuals or those at risk of suicide, or for anything of an abusive or nuisance nature.

All incidents must be kept confidential (you must not talk about it to anyone outside of the charity).

Instructions for completing this form

- This form should be completed by the person dealing with the incident (the person being told about it by the individual, for example, the team member taking the helpline call).
- You should complete it as soon as possible following the incident (so the details are fresh in your mind).
- Please complete it in as much detail as possible, and attach any additional relevant documents (such as any notes you took at the time, helpline calls sheets or procedural forms).
- Please sign and date the form and pass to the relevant line manager or SMT member.

Your details

Name _____

Job title _____

Anyone else involved/informed at the time _____

Details of the individual the incident is about

Name _____

Address (if given) _____

Email _____

Phone number _____

How did they make contact helpline Live Chat email
 forum social media event
 other _____

Details of the incident

Incident type safeguarding act of terrorism
 suicidal threatening/abusive
 nuisance other _____

Date of incident _____ Time _____

Details of the incident

Describe the incident in as much detail as possible. Include any details about the individual, their location (or any indication of where they might be) and the action/proposed action they have taken.

Describe any action you took at the time of the incident.

Unique reference number (if Police were called) _____

Signed _____ Date _____

For any incidents around safeguarding or acts of terrorism, only the safeguarding lead, CEO or SMT on call member can decide whether a breach is necessary. They will be responsible for the final decision.

Looking after yourself

Following any incident it is important to talk to someone about what has happened and how you feel about it. For example, you may feel angry, upset or worried, and talking about this (or 'debriefing') can be an important part of dealing with what's happened, and working through any emotions you are feeling. You can talk to your line manager or a colleague, or you can speak to one of the helpline services team.

Please remember that all incidents are confidential: you must not talk about the details of the incident with anyone outside of the charity without permission from SMT.

In some cases you may feel it would be helpful to have formal counselling following an incident. The charity has access to a confidential, external counselling service for staff members. If you would like to use this service, please contact the HR and H&S Officer to make this request. You will be offered up to six, paid for, sessions either face-to-face or by phone/Skype. No information about the content of the counselling is available to the charity and your line manager will not be informed of your request to access counselling.

You might also need to take some time away from your job, so talk to your line manager about this.

For SMT use only

Action taken _____

Authority called _____

Signed _____ Date _____

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volunteering@lymphoma-action.org.uk



www.lymphoma-action.org.uk/Volunteering

Lymphoma Action Support Services



Helpline (freephone) 0808 808 5555 (Mon-Fri, 10am-3pm)



information@lymphoma-action.org.uk



www.lymphoma-action.org.uk



Live chat via our website (Mon-Fri, 10am-3pm)

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