

Volunteer briefing about sharing information responsibly

Lymphoma Action is committed to providing accessible and trustworthy information for people affected by lymphoma, their families and friends, and healthcare professionals.

All the information we provide has been endorsed by medical and other experts and written by professional medical writers and reviewed by our Reader Panel.

Lymphoma is a complex type of cancer. Our information is here to help and empower people to understand a lymphoma diagnosis, treatment and life with and beyond lymphoma.

For these reasons, we want to take every opportunity to connect people affected by lymphoma to our information.

Sharing information

You provide invaluable support in helping us connect people with information about lymphoma and the work of the Charity. Sharing information must be done responsibly to help people make informed choices for themselves.

It's important to understand the right level of information to share during your volunteering. We set out what information should be shared within the scope of your volunteer role, even if your own knowledge goes beyond that.

Please refer to our briefing sheet about lymphoma and your role-specific guidance.

Increasing your knowledge and understanding

Increasing and updating your understanding of lymphoma and our work is an ongoing process throughout your volunteering.

We have plenty of information and resources to support you with learning more:

- 'What is lymphoma?' animation
- <u>'About lymphoma Action' animation</u>
- Information webpages
- Lymphoma Voices (podcasts)
- Personal stories
- News and blog articles

What volunteers are – and aren't – expected to know

You are likely to be asked questions about lymphoma and the Charity, but you aren't expected to know everything. It's fine to be honest about not knowing the answer or to say that the information is beyond the scope of your volunteer role.

It's always best to signpost people to Lymphoma Action's <u>website</u> where they can read the information for themselves. Alternatively, you can signpost to our Helpline Services:

Monday to Friday, 10am to 3pm



Freephone 0808 808 5555



information@lymphoma-action.org.uk



Live chat available on the website

Signposting

Signposting is an essential aspect of offering reliable information. In addition to information about lymphoma, Lymphoma Action's website provides a list of other <u>useful organisations</u>.

You may be aware of other cancer or health services in your area. It's fine to share information about these, but always give the verbal caveat that you are not endorsing the service and you are unable to give a referral – it's up to the individual to seek and follow up on this information, if they wish.

Sharing your own experience

Everyone's experience of lymphoma will be different, particularly as there are over 60 types of lymphoma with varying presentations, diagnoses and treatment options.

When sharing your own lymphoma experience, make it clear that this is your perspective as others' will be different. What may work for you, may not for others and we have a 'never give advice' rule.

Never give advice

No type of advice, including medical, should be given during your volunteering, even if you are asked for it. You'll need to be clear that you are not permitted to give advice and refer the person to their medical team.

Lymphoma Action is not a registered advice provider and is not insured to give any advice. Therefore, the Charity does not offer advice through any of its services.

Lymphoma Action will not take responsibility for any advice given by volunteers during your volunteering.

Key information about lymphoma

Lymphoma is a type of blood cancer that develops when white blood cells called lymphocytes grow out of control. Lymphocytes are part of our immune system.

Common symptoms

- A lump in your neck, armpit or groin.
- Feeling feel worn out for no reason.
- Losing weight but not sure why.
- **Itching** all the time but not sure why.
- Drenched in **sweat** during the night.

Statistics

- Lymphoma is the **fifth most common cancer** in the UK.
- Every **26 minutes** someone in the UK is diagnosed with lymphoma.
- Lymphoma can **occur at any age**.
- It is the most common cancer among people aged 15-24.

About Lymphoma Action

Lymphoma Action is the UK's only charity dedicated to lymphoma and we're here for everyone, however they are affected.

We've been providing in-depth, expert information for over 35 years. Our mission is to help make sure no one faces lymphoma alone.

Our support services and resources

- Helpline services
- <u>Closed Facebook Group</u>
- Online support meetings
- Buddy Service
- Live your Life (self-management)
- Lymphoma Voices (podcasts)
- Health and wellbeing resources
- Lymphoma Matters Magazine