

Volunteer briefing about lymphoma

The information below covers what you need to know about lymphoma during your volunteering. For example, facilitating a support meeting, talking to people at an event or information stand, or answering questions about lymphoma.

The key points for you to know are in **bold purple** and useful supporting information is in **purple**. If you can remember any of the other information, that's great but don't worry if you can't.

As a volunteer, you are not expected to have a greater level of knowledge about lymphoma than this and you should not go beyond the appropriate level of information as outlined for your role, even if you know a lot more because of your own experience or work.

If someone wants more detailed information, please signpost them either to the Lymphoma Action website and the relevant webpages www.lymphoma-action.org.uk or the Helpline (freephone 0808 808 5555), where our staff can help find and explain the right information. If they need medical advice, suggest they speak with their medical team.

Lymphoma is the fifth most common cancer diagnosed in the UK

The four *most common cancers are breast, lung, prostate, and bowel – all 'solid tumour' cancers.

Every year, more than *20,000 new cases of lymphoma are identified in the UK (figures include Hodgkin lymphoma, non-Hodgkin lymphoma, and CLL).

Around *125,000 people are currently living with lymphoma and someone else is diagnosed every *26 minutes - that's 55 people every day.

Lymphomas are the *most common group of cancers in teenagers and young adults (15-24 years old) and the *third most common group of cancers in childhood (0-14 years old), after leukaemia and brain tumours.

Lymphoma can occur at any age but is most common in two age groups: those under the age of 30, including children, and those over the age of 55.

Lymphoma is nearly always treatable, and most people live for many years after being diagnosed with lymphoma.

*Figures from Cancer Research UK and Macmillan/NCRAS lymphoma incidence and prevalence statistics.

Lymphoma is not well known

Many people haven't heard of lymphoma before their own diagnosis and don't know much about it. Lymphoma doesn't have the word 'cancer' in its name, so people often don't realise it is a cancer, even after diagnosis. Finding out can be a shock.

It affects the lymphatic system, which people are not generally aware of. The lymphatic system consists of vessels – like blood vessels – which run throughout the body, together with the lymph nodes (often referred to as 'glands') and organs such as the thymus and spleen.

Lymphoma is really a complex group of cancers. There are more than 60 'sub-types' of lymphoma, each of which have different courses, treatments and outcomes. This can make lymphoma hard to explain.

A key part of Lymphoma Action's work is to make everyone aware of the disease and its symptoms, to ensure that people are diagnosed as soon as possible and receive the treatment suitable for them.

Lymphoma is regarded as a blood cancer

Lymphoma is included among blood cancers because it involves lymphocytes, a type of white blood cell. Lymphocytes are carried around the body in both the blood and the lymphatic system.

Lymphocytes are an important part of the immune system, which is the body's defence against infection and toxins, so lymphoma can also be described as a cancer of the immune system.

With some exceptions, lymphoma is usually treated in the haematology (blood diseases) department of hospitals, rather than the oncology (cancer) department. Other blood cancers are myeloma and leukaemia.

Lymphoma occurs when lymphocytes grow out of control

Healthy lymphocytes travel around the lymphatic system in a pale fluid, called lymph, collecting in the lymph nodes, ready to fight infection. When the body spots an infection, the lymphocytes increase numbers rapidly, through cell division. They are then ready to carry out their immune function.

In lymphoma, changes in someone's genes mean the lymphocytes divide abnormally or do not die when they have completed their function, or the body no longer needs them.

The abnormal lymphocytes collect in the lymph nodes, which become enlarged. Those near the surface in the armpits, neck or groin often becoming noticeable symptoms and signs of lymphoma (swollen lymph nodes).

The lymphatic system takes lymphocytes all over the body to fight infections, so lymphoma could start in almost any part of the body.

The causes of lymphoma are not yet fully understood

Doctors and researchers know that lymphoma starts with changes to the genes in lymphocytes but not so much about why these changes happen.

However, it is known that **lymphoma is not inherited** (passed down from parents to their children) **and that it can't be caught from someone or given to anyone else.**

There is no evidence that anything an individual has done – or not done – has caused them to develop lymphoma.

There are known risk factors, which are things that make lymphoma a bit more likely but are not a direct cause. Risk factors might include having other problems with the immune system, having certain viral or bacterial infections, having a close relative with lymphoma, and getting older. However, millions of people have one or more of these risk factors and never develop lymphoma.

Lymphoma is often difficult to diagnose

People often don't know that their symptoms could mean they have lymphoma, so they might have them for a long time before going to the doctor.

They also might not realise their symptoms could be connected and so might not mention some of them to the GP. Most of the symptoms are also common to other health conditions, which is why GPs often rule out more common health conditions before recognising it as a lymphoma.

Many people have no symptoms at all – they are 'asymptomatic' – and are only diagnosed through investigations for another condition.

Several tests and scans, for example a biopsy or a CT scan, are usually done to confirm it is lymphoma and determine which sub-type it is.

For all these reasons, it can take some time to reach the right diagnosis, but this is essential to ensuring the right treatments are considered.

The key symptoms of lymphoma are:

- **swollen lymph nodes, a painless lump(s) or swelling in the neck, armpits or groin**, where there are large, prominent lymph nodes ('swollen glands', caused by infection, are usually painful and reduce in size when the infection clears)
- **fatigue**, or unusual tiredness, often without exertion, which doesn't improve much with rest
- **unexplained weight loss**
- **developing infections more easily and having difficulty recovering from them**

- **drenching sweats, especially at night**, often requiring a change of bed linen and nightclothes
- **persistent itching**, in one place or all over the body, which isn't relieved by scratching
- fever, a temperature above 38°C or 100.4°F.

This is not an exhaustive list – some lymphomas might have other symptoms. Not all sub-types produce all of these symptoms, while some have other symptoms, such as persistent coughing or breathlessness, abdominal pain or diarrhoea.

Anyone with these symptoms should make an appointment to see their GP.

Most lymphomas are given a 'stage', 1 to 4, which indicates where in the body the lymphoma has been found. Stages 1 to 2 are early stage, and 3 to 4 are advanced stage. In lymphoma, staging refers to how much of your lymphatic system is affected by lymphoma, so it's not uncommon to be diagnosed with stage 4 lymphoma.

There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma

Hodgkin lymphoma has two main types, one more common than the other, but they are both fast-growing cancers that need treatment straight away.

Non-Hodgkin lymphomas are divided into **high-grade** (fast-growing or 'aggressive') lymphomas that need treatment straight away, and **low-grade** (slow-growing or 'indolent') lymphomas that may not need treatment straight away or for a long time. Another way of classifying non-Hodgkin lymphomas is by which type of lymphocyte they develop from - T-cell or B-cell types. T-cell types are rare, while B-cell types are, relatively, more common.

High-grade and low-grade lymphomas are each divided into many sub-types. Altogether, there are more than 60 sub-types of lymphoma.

Different types of lymphoma are managed differently

Hodgkin and high-grade non-Hodgkin lymphomas need immediate treatment, usually with the aim of curing them. Sometimes, these lymphomas can come back and require further treatment.

Low-grade types might not require treatment straightaway, and some people never need treatment at all. Instead, patients are put on an **active monitoring** programme (also known as 'watch and wait') that monitors the growth of the lymphoma until the point at which treatment is required. Treatment aims to reduce symptoms, rather than curing the lymphoma. People can live with these chronic cancers for many years, having treatment periodically.

Low-grade lymphomas are managed differently to what most people expect after a cancer diagnosis, which can be hard to understand and come to terms with.

Low-grade lymphomas can sometimes ‘transform’ into high-grade sub-types, which require immediate treatment.

There is a wide range of treatments for lymphoma

Most commonly, people will receive chemotherapy, but there are other treatments available (for example, radiotherapy, and targeted treatments and antibody therapy).

The treatment given depends on the type and ‘stage’ of the lymphoma (where it is located in the body), side-effects and how severely someone experiences them, the patient’s age and general health, the effects a treatment might have on them in later years (late effects), and their own priorities and preferences. **This means two people with the same sub-type of lymphoma might have two completely different treatments.**

Treatment might lead to a ‘complete remission’, where there is no sign of the lymphoma in tests and scans.

However, treatment might not get rid of the lymphoma completely, known as ‘partial remission’. Sometimes ‘maintenance therapy’ might be given to prolong the remission.

For some people, their lymphoma might come back after treatment (relapse), which is then followed by further treatment in the months or years ahead.

Subsequent or ‘second line’ treatment might be different, depending on the lymphoma and/or the patient. As well as the types above, second line treatment for some types may include a stem cell transplant or CAR T-cell therapy.

Lymphoma Action Helpline Services

Monday to Friday, 10am to 3pm:



Freephone 0808 808 5555



information@lymphoma-action.org.uk



Live chat available on the website