

Lymphoma

action



Nodular lymphocyte predominant Hodgkin lymphoma

Also known as nodular lymphocyte
predominant B-cell lymphoma

Acknowledgements

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If you would like to make a donation to Lymphoma Action to help us continue providing information and support to people affected by lymphoma, you can do so at lymphoma-action.org.uk/Donate



My lymphoma type, stage and date of diagnosis:

My treatment plan:

Key contact

Name: _____

Role: _____

Contact details: _____

Job title/role	Name and contact details
GP	
Consultant haematologist / oncologist	
Clinical nurse specialist (CNS) or key worker	
Emergency hospital contact	

About this book

Nodular lymphocyte predominant Hodgkin lymphoma (NLPHL) is a rare, slow-growing, type of lymphoma. This book explains what NLPHL is, how it is diagnosed, and the treatment options available.

You might also be interested in our book *Living with and beyond lymphoma*, which gives tips on coping practically, physically and emotionally.

Words in **bold teal** are explained in the glossary on pages 74 to 77.

You can find our full range of resources on our website. If you can't find the information you're looking for, or in the format you would like, please contact us (see page 78).

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“ A cancer diagnosis is always scary. There’s a lot to process and come to terms with. Life changes in an instant. My way of coming to terms with what was going on was finding out as much information as I could about the disease and getting emotional support.

Robert, diagnosed with NLPHL

What is nodular lymphocyte predominant Hodgkin lymphoma (NLPHL)?

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What is lymphoma?

Lymphoma is a type of blood cancer. It develops when **white blood cells** called **lymphocytes** grow out of control.

Lymphocytes are part of your **immune system**, which helps to fight infection. Lymphocytes travel around your body in your **lymphatic system** in a fluid called lymph.

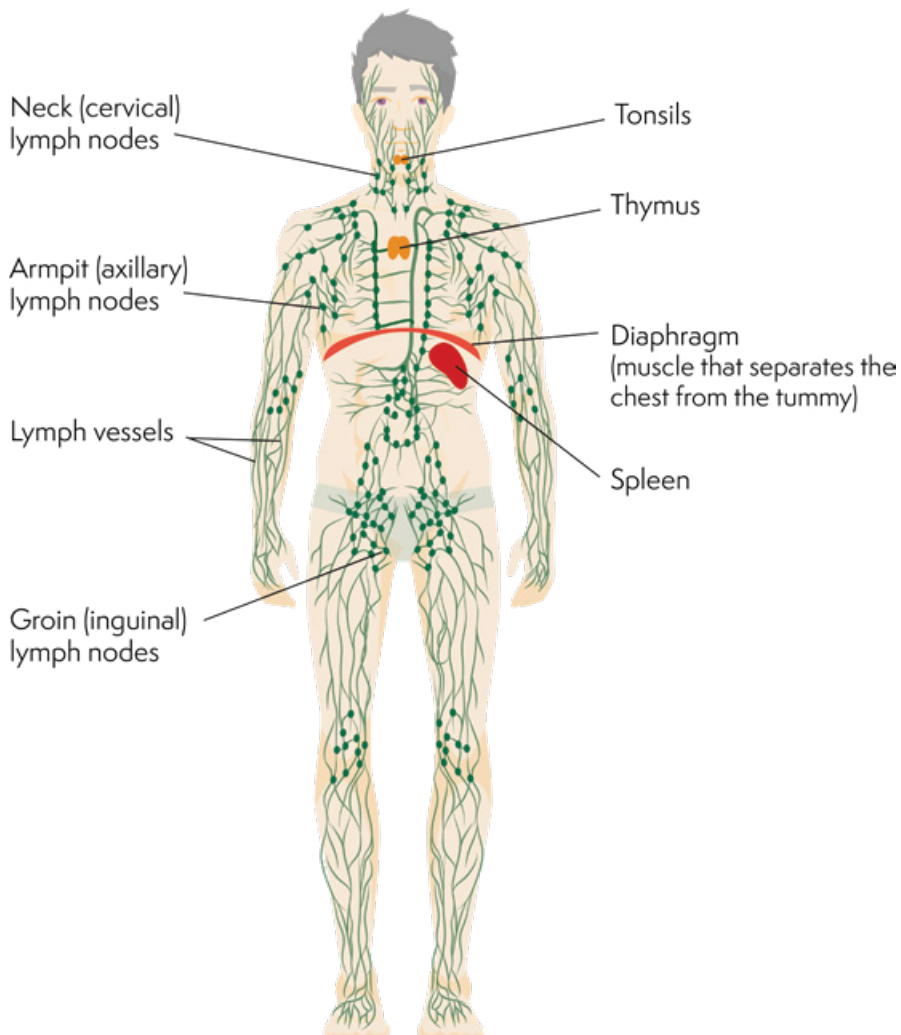
The lymphatic system is a network of lymph vessels and **lymph nodes** (sometimes known as lymph glands). It also includes organs, such as your **spleen** and **thymus**.

If you have lymphoma, your lymphocytes divide in an abnormal way or do not die when they should.

The abnormal lymphocytes build up, usually in lymph nodes in your armpits, neck or groin. However, they can collect in almost any part of your body.



Find out more and watch a short animation on our website, lymphoma-action.org.uk/WhatIsLymphoma



The lymphatic system



Find out more about the lymphatic system on our website, lymphoma-action.org.uk/LymphaticSystem

Types of lymphoma

There are over 60 different types of lymphoma. They are broadly grouped into Hodgkin lymphomas and non-Hodgkin lymphomas. Different types of lymphoma behave differently and need different treatment.



Find out more about the different types of lymphoma on our website lymphoma-action.org.uk/Types

Hodgkin lymphoma contains cells called Reed–Sternberg cells. Doctors can see these cells when they look at a sample of the lymphoma under a microscope.

NLPHL contains a variant of these Reed–Sternberg cells called lymphocyte-predominant (LP) cells. They are sometimes called ‘popcorn cells’ because they look a bit like pieces of popcorn under a microscope.

You might hear NLPHL called ‘nodular lymphocyte predominant B-cell lymphoma’ as the International Consensus Classification (ICC) now classifies it as a low grade B-cell lymphoma rather than a Hodgkin lymphoma. This is because it is often treated in a similar way to other low-grade B-cell lymphomas.

Who gets NLPHL?

NLPHL is rare. Around 220 people are diagnosed with it in the UK every year. It can develop at any age, although it's most common in people in their 30s to 50s. It can also affect children and young adults.

NLPHL is much more common in males than females, but scientists don't know why.

There is no known cause for most cases of NLPHL.



We produce a *Young person's guide to lymphoma* for people aged between 15 and 24. Visit lymphoma-action.org.uk/Shop to order your free copy.

“

Like many people in their 20s, I thought I was invincible. I never thought anything could be seriously wrong. So I was totally shocked when I was told I had nodular lymphocyte predominant Hodgkin lymphoma, a slow growing type of lymphoma. It took a while to sink in that I had cancer.



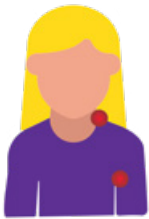
Adam, diagnosed with NLPHL

Symptoms of NLPHL

The symptoms you have depend on which parts of your body are affected. Usually, symptoms start to go away once you start treatment.



Find out more about symptoms at lymphoma-action.org.uk/Symptoms



The most common symptom of NLPHL is a lump or lumps. These are swollen lymph nodes. They are usually painless and feel rubbery when you touch them. They are most often found in the neck, armpits or groin, but they can develop in other places too.

Swollen lymph nodes are often the only symptom. They can slowly enlarge over months or years.

It is important to remember that lymph nodes can swell for lots of reasons. Most people with swollen lymph nodes do not have lymphoma.

“ *I had raised lymph nodes in my neck, and could feel small lumps which felt very mobile. At the time I thought it was just my lymphatic system doing its job.*

Surinder, diagnosed with NLPHL



Sometimes, people have other symptoms, such as:



Fever: a high temperature of above 38°C/100.4°F, that might come and go.



Drenching sweats: especially at night.



Unexplained weight loss: losing weight quickly without trying to.

These three symptoms are known as '**B symptoms**'. Whether or not you have B symptoms can affect which treatment options are most appropriate for you.

Speak to your medical team for advice to help you manage any symptoms you are experiencing.

You can find tips to help you cope with symptoms of lymphoma on our website (search 'coping with symptoms') and in our book *Living with and beyond lymphoma* available from lymphoma-action.org.uk/Books



Outlook

NLPHL doesn't always need treatment, it can sometimes be managed with **active monitoring** (page 38).

NLPHL usually responds very well to treatment. Most people either go into **complete remission** (disappearance of the lymphoma) or a **partial remission** (significant shrinkage of the lymphoma to a level where it is not causing troublesome symptoms).

Although treatment is very effective, NLPHL can come back (**relapse**) and need more treatment (page 47). Relapsed NLPHL usually responds very well to treatment.

For most people, having NLPHL will have little or no effect on how long they live.

Your medical team are best placed to advise you on your outlook based on your individual circumstances.

Occasionally, NLPHL can change (transform) into a faster growing type of lymphoma. This is uncommon. It happens in around 1 in 100 people with NLPHL each year. Transformed lymphoma needs stronger treatment. It is usually treated like a type of fast-growing (high-grade) non-Hodgkin lymphoma called **diffuse large B-cell lymphoma (DLBCL)**. Transformed NLPHL often responds well to treatment and many people go into complete remission.

Summary

- Lymphoma is a type of blood cancer.
- It develops when white blood cells called lymphocytes grow out of control.
- NLPHL is a rare slow-growing type of lymphoma.
- NLPHL is more common in men than women.
- Most people diagnosed with NLPHL are aged between 30 and 60, but it can affect anyone.
- In most cases, the cause is unknown.
- The most common symptom is a swollen lymph node or nodes.
- Speak to your medical team for advice about how to cope with any symptoms you experience.
- The long-term outlook for people affected by NLPHL is generally very good.



“ I had a PET/CT scan, which showed I had loads of tiny clusters around my collar bone, some by my spleen and some in my chest. My diagnosis was confirmed as NLPHL, stage 3S.

Surinder, diagnosed with NLPHL

Tests, diagnosis and staging

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Diagnosis

Your GP is likely to be the first person you speak to about any symptoms or health concerns.

Your GP will ask you about your symptoms and check for any swollen (enlarged) lymph nodes. This alone can't tell them whether or not you have lymphoma – you'll need to have tests and scans to find out more.

You'll be referred to a hospital specialist and seen quickly if your GP thinks there is a possibility that you might have lymphoma.

Once you are referred to a hospital specialist, you're likely to need further tests and scans. You have most of these tests as an outpatient, which means that you don't have to stay in hospital overnight. It's important that your medical team get all the information they need about your lymphoma so that they can plan the most suitable treatment for you.

We outline some of the most common tests and scans for lymphoma in this section. You might not need all of them, but you will need a **biopsy** (page 19) to confirm a diagnosis of lymphoma.



For more information about tests and scans, visit lymphoma-action.org.uk/Tests

Blood tests

Most people have blood tests as part of their diagnosis for lymphoma, and then throughout treatment.

Blood tests can help doctors see how the lymphoma is affecting your body, and plan the best treatment for you.

Blood tests can check:

- your general health.
- your blood cell counts. Lymphoma and its treatment can lower your levels of red blood cells, white blood cells and platelets. This can cause problems that might need treatment. You might also need to take some extra health and safety precautions.
- for signs of inflammation. This can be a sign of infection and might need treatment.
- how well your kidneys and liver are working. Sometimes, lymphoma and its treatment can affect the functioning of these organs.

Biopsies

Lymph node biopsy

A procedure called a **lymph node biopsy** is needed to confirm whether or not you have lymphoma.

This involves removing a swollen lymph node, or a sample of cells from it. A needle core biopsy is the most common type of biopsy used, which is done under local anaesthetic. Sometimes a larger sample is required, and a surgical excision biopsy is used. This type of biopsy requires a general anaesthetic.

A specialist examines the sample under a microscope and does tests on it to find out what type of lymphoma it is.

Speak to a member of your medical team in advance of the day of having your biopsy if you feel worried about it.

You can usually go home on the same day as having a biopsy. You shouldn't drive yourself home if you have had a sedative or a general anaesthetic. Speak to a member of your medical team for help organising transport if this is difficult for you to arrange.

You should be given clear guidance about how to care for the biopsy site to help prevent infection. **It is important to contact your medical team straightaway if you have any problems with the wound or notice any signs of infection.** This includes bleeding, swelling, discharge from the biopsied area, fever (a temperature above 38°C/100.4°F), chills and sweating.

Bone marrow biopsy

A **bone marrow** biopsy checks whether you have lymphoma in your bone marrow. This is often not needed as a PET/CT scan (page 22) can be effective in checking for lymphoma in your bone marrow.

Bone marrow is the spongy tissue in the middle of your larger bones. It is where blood cells are made.

A bone marrow biopsy sample is usually taken from your hip bone (pelvis). You have a local **anaesthetic** to numb the area. The doctor or nurse inserts a biopsy needle into the

middle of the bone to collect a sample – either by hand or with a small electronic device. The whole procedure usually takes 10 to 15 minutes.

A bone marrow biopsy is a safe procedure. However, you should contact your medical team if you develop any of the following:

- fever (temperature above 38°C/100.4°F)
- pain where the sample was taken that gets worse or that lasts more than a few days
- redness or swelling where the needle went in
- bleeding that doesn't stop when you apply pressure.

These could be signs of infection or a complication that needs prompt medical attention.

Scans

Different types of scans are helpful for different things. They might be used to:

- diagnose and **stage** lymphoma
- show the best place to take a biopsy sample from
- plan your treatment
- check your response to treatment
- check for any signs of **relapse**.

Usually, you have a scan at your local hospital as an outpatient. If your local hospital doesn't have the right scanning machine for you, you might be able to have a scan at a mobile unit or have to travel to a hospital that's further away.

Scans aren't painful, but you might find it uncomfortable if you have to lie still for a long time. Speak to a member of your medical team if you feel anxious about any aspect of having a scan. You might find it helps to talk through what to expect. In some cases, you might be offered a sedative – but talk to them about this in advance of the day, to see if it's suitable for you and to give them time to arrange it.

PET/CT scans

Computed tomography (CT) scans and positron-emission tomography (PET) scans are the most common scans doctors use for people affected by lymphoma.

Usually, they're done in the same appointment, as a **PET/CT scan**. A PET/CT scan can help give a clear picture of which areas of your body are affected by lymphoma.

CT uses lots of X-rays to take pictures through your body. They're better than regular X-rays at taking pictures of the organs inside your body, including lymph nodes.

PET uses a harmless radioactive sugar to look at the level of activity of cells in your body. Cells that are more active, such as lymphoma cells, take up more sugar than less active cells. A special camera detects the radioactivity and these show up as 'hot spots' on the scan image.

You will be given advice on anything you need to do to prepare you for your scan. This might include being:

- asked not to eat or drink (known as fasting) for a few hours before you have your scan
- given a special dye (contrast agent) as a drink or an injection before your scan – this helps to show up certain parts of your body more clearly on the scan image
- given guidance about if and when to take any medication you usually take
- advised not to do strenuous physical activity in the 24 hours before your scan.

Staff will ask you to remove any metal you're wearing and whether you could be pregnant.

Some scans use very low levels of radiation. You will not be radioactive after a CT scan alone. However, with a PET/CT scan, you give off very low levels of radiation afterwards. Your medical team will tell you how long this is likely to be for. As a precaution, you should avoid being close to women who are pregnant during this time.

Other scans

Other scans might be used. These include:

- **Ultrasound scans** use high-energy soundwaves to take pictures of the inside of your body. You might have an ultrasound scan to examine lymph nodes that are near the surface of your skin or to help your doctor find the best place to take a biopsy. You'll be given information about how to prepare for your ultrasound scan. Ultrasound scans are quick and painless, and you can go straight home afterwards.

- **X-rays** use high-energy waves, similar to radio waves to take pictures through your body. You might have an X-ray to check for swollen lymph nodes inside your chest or the position of a central line (central venous catheter) if you need one for chemotherapy (page 45). You have to sit, stand or lie still to have an X-ray. It does not hurt and only takes a few minutes.
- **Magnetic resonance imaging (MRI)** scans use strong magnets to take pictures of the inside of your body. You might have an MRI scan if you are allergic to the contrast agents used in CT and PET/CT scans, or are pregnant, to avoid radiation. You'll need to take off any metal that you're wearing before your scan. Tell your medical team if you have any metal in your body, including a pacemaker, hip replacement, implantable defibrillators, ear (cochlear) implants, staples from surgery and metal plates put in after an injury. For the scan, you lie on a bed that moves into a tube, and you have to keep very still for up to an hour. The MRI machine is very noisy – you should be offered earplugs and might be able to listen to music.



For more information about each of these types of scan, visit lymphoma-action.org.uk/Tests

Test results

Your medical team gather as much information as possible from your tests and scans. You then have an appointment to discuss the results of the tests. You can ask to take a family member or a friend to be with you if you would like to.

Many people find the uncertainty of waiting for results of tests and scans very challenging to deal with. You can ask your doctor for an idea of how long you'll need to wait for your results.



We have tips on coping with waiting for test results – visit lymphoma-action.org.uk/Waiting

Finding out you have lymphoma can be a shock. You're likely to experience a mix of feelings and emotions – there's no typical way to feel.



We offer a range of support services for anyone affected by lymphoma, including family and friends of those diagnosed. These include a Helpline, Online Support Meetings, trusted information in a range of formats, and personal stories from others with a lived experience of lymphoma. See our full range of support at lymphoma-action.org.uk/Support

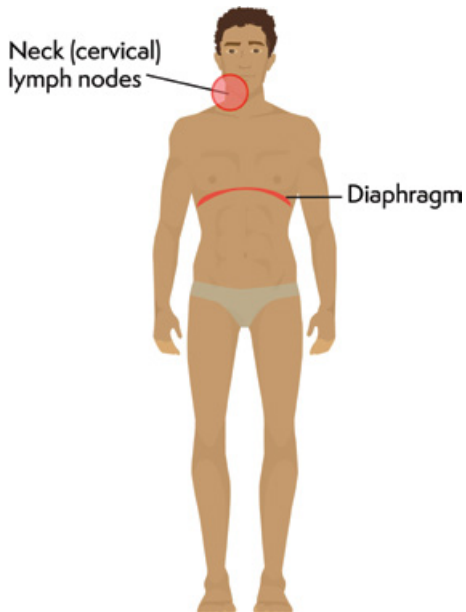
Staging

‘Staging’ is the process of working out which parts of your body are affected by lymphoma. The results of your tests and scans help doctors to work out the stage of your lymphoma. This is important because it helps your medical team plan the most appropriate treatment for you.

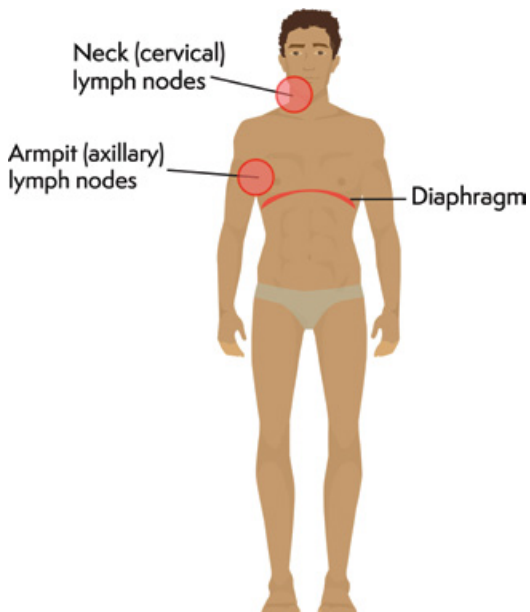
There are four main stages of lymphoma, numbered 1 to 4. These are sometimes written in Roman numerals (I,II, III and IV).

You might also have letters after your stage number. For example, you might be stage 2A, or stage 3E.

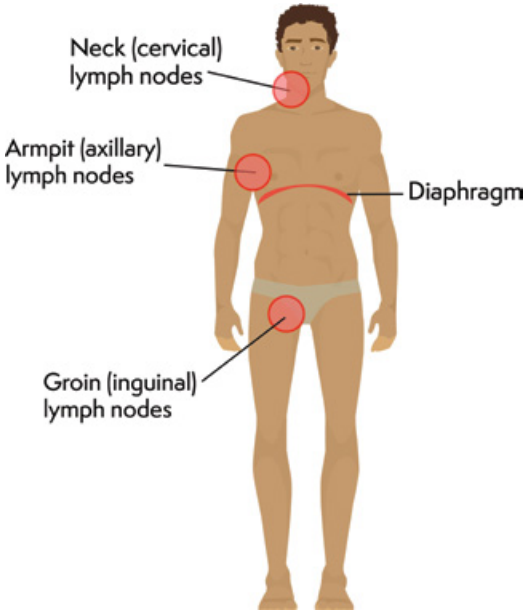
- A** You don't have any **B symptoms**.
- B** You have one or more B symptoms (weight loss, night sweats or fevers).
- E** Extranodal lymphoma means that the lymphoma started outside the lymphatic system.
- S** Lymphoma is in the spleen (part of the lymphatic system).
- X** One or more of your affected lymph nodes is considered to be large or ‘bulky’.



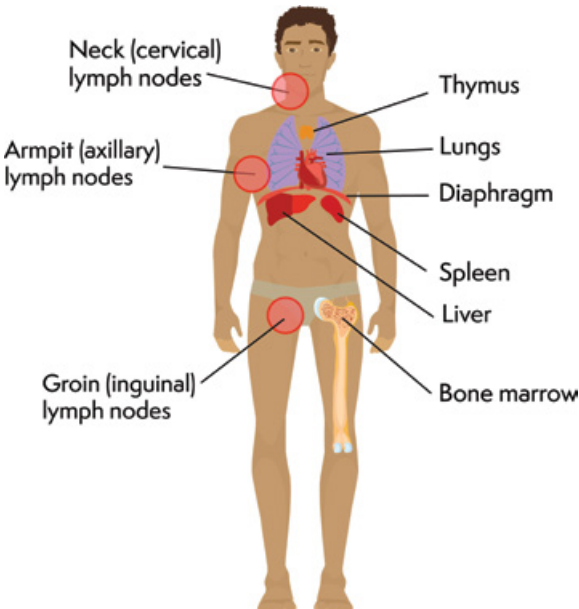
Stage 1 Lymphoma is in only one group of lymph nodes (gland). This could be anywhere in your body.



Stage 2 Lymphoma is in two or more groups of lymph nodes. These could be anywhere in your body, but all on the same side of your diaphragm.*



Stage 3 Lymphoma is in lymph nodes on both sides of your diaphragm.*



Stage 4 Lymphoma has spread from the lymph nodes to an organ outside of the lymphatic system (for example, to the liver, lungs, bone marrow or solid bones).

* The diaphragm is the muscle separating your chest from your tummy.

“ *A CT and PET scan had shown that the lymphoma was in my neck, chest, stomach, spleen and in my bone marrow. I was diagnosed with nodular lymphocyte predominant Hodgkin lymphoma, stage 4.*
Sophie, diagnosed with NLPHL



Your doctors might talk about ‘early’ stage or ‘advanced’ stage NLPHL. ‘Early’ stage means either stage 1 or stage 2 without B symptoms. ‘Advanced’ stage generally means stage 2 with B symptoms, stage 3 or stage 4.

Your lymphatic system runs throughout your body, so, quite often, lymphoma is advanced when it is diagnosed. Unlike many other cancers, advanced stage lymphoma can be successfully treated.

“

When I was told I had stage III NLPHL, I was very shocked. Since I hadn't really had any symptoms, I realised that I must have been living with this disease for months - and maybe years - pretty much symptom free.

Robert, diagnosed with NLPHL



Summary

- NLPHL is usually diagnosed using a lymph node biopsy.
- You have other tests such as blood tests and a PET/CT scan to find out which parts of your body are affected by lymphoma (staging).
- The results of your tests and scans help your doctor plan the most suitable treatment for you.
- Speak to a member of your medical team if you have questions about any tests you're having, or if you feel worried about having them.
- Your medical team can give you an idea of how long it will be before your test results are available.



Notes



“ *I am currently on active monitoring (or watch and wait) and feel really confident in my oncologist. Initially I attended the clinic every three months to have my bloods taken, weight checked and talk about how I'm feeling. This has now been moved to every four or five months.*

Sophie, diagnosed with NLPHL

Treatment

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Your medical team

Your treatment is planned by a multidisciplinary team (MDT) made up of different professionals. They each have knowledge and expertise in different specialist areas. This ensures you are offered the best care.

The team meets to discuss and plan your treatment, taking into account your individual needs, general health and preferences.

The person who has overall responsibility for your care is a doctor who specialises in treating people who have cancer. This is a consultant oncologist or haematologist.

You will have a key worker who you can contact with any questions or concerns. Usually, your key worker is your **clinical nurse specialist** (CNS). They can help you to identify and manage any issues that arise from living with lymphoma. This includes any needs that are practical, financial, physical, emotional and social. To help with this, they sometimes use a questionnaire, often referred to as a Holistic Needs Assessment or 'HNA'.

You should be given the name and contact details of your key worker – if you're not given this information, ask your lymphoma consultant for it.

Treatment options

The treatment your medical team will recommend for you depends on the stage of your disease and how it is affecting you. Your medical team are likely to consider different treatment options depending on whether you:

- have early disease (stage 1 or stage 2 without B symptoms) – page 27
- more advanced disease (stage 2 with B symptoms, stage 3 or stage 4) – page 28.

They also consider factors such as:

- your symptoms
- your age and general health
- your feelings about the treatment options
- whether or not you plan to have children in the future
- any potential side effects
- any potential late effects (health problems that develop months or years after treatment).

If appropriate, your consultant can refer you to a fertility specialist before you start treatment.

Treatment for early stage NLPHL

Most people with NLPHL have early stage lymphoma (stage 1 or stage 2 without any B symptoms) when they are diagnosed. This means the lymphoma is only growing in one place, or a few places close together. If you have early stage NLPHL, you might only need treatment to the area affected by lymphoma.

If your lymphoma is in a place where it can be removed, you might be offered surgery. If you have no signs of lymphoma left after surgery, you might not need any more treatment. Instead, your medical team might recommend that you have regular check-ups to make sure the lymphoma stays under control. This is called **active monitoring** (active surveillance or 'watch and wait', page 38). If there are lymphoma cells left behind after your surgery, your medical team are likely to recommend a course of radiotherapy (page 40) too.

If you have early stage NLPHL that can't be removed, you might have radiotherapy to the part of your body affected by lymphoma. This is usually very successful.

If these options aren't suitable for you, your team are likely to suggest the same treatment options used for people with advanced stage NLPHL.

Treatment for advanced stage NLPHL

Around 1 in 4 people have advanced stage NLPHL (stage 2 with B symptoms, stage 3 or stage 4) when they are diagnosed. Advanced NLPHL still responds very well to treatment. The main difference is that you have treatment to your whole body rather than just one area.

If you have advanced-stage NLPHL but your symptoms aren't interfering with your day-to-day life, you might not need treatment straightaway. Instead, your medical team might recommend **active monitoring** (active surveillance or 'watch and wait', page 38). This involves having regular check-ups to monitor how the lymphoma is affecting you.

If your lymphoma needs treatment, you are most likely to have **chemotherapy** combined with the antibody treatment, **rituximab**. This is known as **immunochemotherapy** (page 42).

“ *It was explained to me that I could have a period of active monitoring (watch and wait) or they could consider starting treatment with immunochemotherapy straightaway. Although radiotherapy can be an option for NLPHL, they said it was not appropriate in my case. I felt very strongly that I wanted to start treatment straightaway and made my preference very clear to my treating team.*



Surinder, diagnosed with NLPHL

Active monitoring

Sometimes there is no benefit in having treatment if the lymphoma is not causing problems. Instead, you have regular check-ups to monitor how the lymphoma is affecting you. This is called active monitoring (also known as active surveillance or watch and wait).

Active monitoring does **not** mean there is no suitable treatment for you. It means that, while you are well, you can avoid the side effects of treatment for as long as possible. Treatment is still available if your lymphoma starts to cause problems or if you develop symptoms that are hard to cope with. Treatment is just as successful in people who save it until they need it as in people who have treatment straightaway.

When you are on active monitoring, you have regular check-ups with your medical team to make sure your lymphoma doesn't need treatment. They will talk to you about how you are feeling and whether you've noticed any change in your symptoms.

If you are worried about your health at any time, contact your medical team. You don't have to wait for your next appointment.



We produce a separate book on active monitoring, visit lymphoma-action.org.uk/Shop to order your free copy.

Active monitoring can bring a range of feelings and emotions. Some people feel relieved that they don't need to start treatment straightaway. Others find it hard to be told they have lymphoma but that it's not being treated.



We're here for you. Visit lymphoma-action.org.uk/Support to find out all the ways we can support you.

“ *Hearing I had cancer one moment, and then being told we were going to wait and watch was quite challenging. The messaging I've heard all my life was the earlier the diagnosis – and by implication, treatment – the better the outcome. I assumed I'd be on a fast-track to chemo because I was stage III.*
Robert, diagnosed with NLPHL



Radiotherapy

Radiotherapy uses high-energy X-rays (a type of radiation) to destroy cancer cells. It stops them from dividing, so that they die off in time.

Radiotherapy is a 'local' treatment, which means that it affects only the parts of your body being treated. It is therefore usually used to treat lymphoma that is only in one or two places in your body

Many people who have radiotherapy have it with the aim of getting rid of the lymphoma – this is known as 'curative radiotherapy'. Sometimes, radiotherapy is given to help shrink the lymphoma. This can help control symptoms and is known as 'palliative radiotherapy'.

You'll need to go to hospital to plan your radiotherapy and each time you have it. Not all hospitals have a radiotherapy department, so you might need to travel a bit further to one that does.

Your treatment is carefully planned by a radiotherapy team. They usually use a computed tomography (CT) scan to help them work out:

- the total dose of radiotherapy to give you
- how many separate treatments (fractions) you should have
- exactly where the lymphoma is, so that they can direct radiotherapy to precisely the area.

You might have some tiny permanent dot-like marks made to your skin, using a needle and ink. These are lined-up with the X-ray beams on the radiotherapy treatment machine to help make sure that the radiotherapy goes to exactly the right place.

If you are having radiotherapy to your head or chest area, you might instead have a plastic radiotherapy mask (sometimes called a 'shell') to wear each time you have treatment so that the radiotherapy goes to exactly the right place.

Each radiotherapy session takes around 10 to 20 minutes. Most of this time is spent getting you into position – the treatment itself takes only a few minutes. Having radiotherapy doesn't hurt.

Typically, you have radiotherapy treatment Monday to Friday for 2 to 3 weeks. However, your schedule might differ from this as your treatment plan is designed specifically for you.

During the treatment, the radiotherapy staff have to leave the room but they can see you and hear you all the time.

Radiotherapy treatment does not make you radioactive. People around you, including children, are not at any risk from being near to you after you've had treatment.



Read more about radiotherapy for lymphoma, including answers to frequently asked questions, on our website at lymphoma-action.org.uk/Radiotherapy

Immunochemotherapy

Immunochemotherapy is chemotherapy combined with antibody therapy.

Chemotherapy is treatment with drugs. It works by either stopping lymphoma cells from dividing or triggering lymphoma cells to die.



Watch our short animation explaining how chemotherapy works at lymphoma-action.org.uk/Chemotherapy

Antibody therapy is a type of targeted treatment. Antibody therapy uses antibodies that have been specially made in a lab. They are designed to recognise and stick to a protein on a cancer cell. This activates your immune system to destroy the cancer cell.



Find out more about antibody therapies on our website at lymphoma-action.org.uk/TargetedTreatments

Regimens

Immunochemotherapy is given as a regimen – a treatment plan that includes more than one type of drug. The different drugs work on different phases of the cell cycle, helping to kill as many lymphoma cells as possible.

Your treatment is planned specifically for you.

There are a range of immunochemotherapy **regimens** available – these include:

- **R-CVP**. Made up of rituximab, cyclophosphamide, vincristine and prednisolone.
- **R-CHOP**. Made up of rituximab, cyclophosphamide, doxorubicin (or hydroxydaunorubicin), vincristine (Oncovin®) and prednisolone.
- **R-ABVD**. Made up of rituximab, doxorubicin (Adriamycin®), bleomycin, vinblastine and dacarbazine.

People who are not well enough to have chemotherapy might have rituximab on its own.

Search 'chemotherapy drugs' at macmillan.org.uk to find out more about particular chemotherapy drugs or regimens.

Cycles

Immunochemotherapy is given as a number of treatments or 'cycles'. After each cycle of treatment, you have a rest period, to allow your body to recover.

During each cycle, you might have to go to hospital once, or on a number of days. This depends on the exact immunochemotherapy regimen you have.

Immunochemotherapy is given in cycles because the drugs work on cells that are in the process of dividing – they don't have much effect on cells that are not dividing. Having it

in a number of treatments at different times increases the chances of it affecting dividing lymphoma cells.

In between your treatment days, you usually have medicines to take at home. Some of these might be part of your treatment plan (regimen). Others are to help control any side effects of treatment (page 58).

Having immunochemotherapy

Before having immunochemotherapy you usually have blood tests to check that your blood counts are at a level that is considered to be safe for you to have treatment. If your blood counts are low, your medical team might advise waiting for a little while before having treatment, until they are higher. You might also be given treatment to help boost your blood cell counts (page 54).

You usually have immunochemotherapy for NLPHL as an outpatient, in a day case unit or chemotherapy unit. You go to the hospital on treatment days and can go home afterwards.

Most immunochemotherapy drugs are given **intravenously** (as a drip or injection into a vein). Your nurse can inject some drugs over a minute or two. Other drugs have to be given more slowly through a drip (infusion). This could take anywhere from 30 minutes to a number of hours, depending on the drugs you have.

Intravenous (IV) drugs are given through a cannula or a central venous catheter.

- A cannula is a small, soft plastic tube that usually goes into a vein in your arm. You have a new one put in each time you go for treatment.
- A central venous catheter (or 'central line') is a longer plastic tube that goes into a larger vein near your heart. A central line usually stays in for the whole of your treatment. A line can also be used to give you other drugs and fluids and to take blood samples for tests more easily. They can save you the discomfort of repeated needle pricks.



There are different types of line. Visit lymphoma-action.org.uk/Chemotherapy to find out more.

Lines are put in during a small operation under local or general anaesthetic. Once it's in place, a line isn't usually painful. However, if you feel any discomfort, tell a member of your medical team. Once it's fitted, your line is covered with a simple dressing to protect it. You will be given instructions on how to care for it once you go home, including how to take baths and showers.

Lines can sometimes become infected. Occasionally, a blood clot can develop around them. Contact your hospital immediately if you develop any symptoms of infection, including:

- redness or heat around the area (site) of the line
- a high temperature (above 38°C/100.4°F)
- swelling in your arm.

Tell your nurse if you feel any discomfort when you are having IV immunochemotherapy. They can check that the drugs are going in properly and make any adjustments they need to.

Some drugs are given by an injection into muscle (intramuscularly) or injection under the skin (subcutaneously).

Some drugs can be taken by mouth (orally) as a tablet or capsule. Unless you've been told to by a member of your medical team, do not crush or open the tablets or capsules.

You should be given guidance about how to store and take any drugs that you're given to take at home. If you are not told how to do this, ask your clinical nurse specialist or another member of your medical team.

It is important that other people don't handle your drugs. If you are helping someone to take immunochemotherapy, wear protective gloves when handling the drugs.

Safety precautions

Your medical team will give you guidance about any safety precautions you should take while you are having immunochemotherapy.

Take steps to lower your risk of infection. Be aware of the possible signs and symptoms of infection and who to contact if you notice any of them (page 55).

While you are on chemotherapy treatment, use a condom to avoid passing chemotherapy to your partner during vaginal, anal or oral sex. This also protects you against infection.

Talk to your medical team if you want to have a baby. People who have had lymphoma are usually advised to wait for up to 2 years after finishing treatment before trying to start a family.

If NLPHL comes back

Treatment for NLPHL is usually effective. However, it can sometimes come back (**relapse**) and need more treatment. Occasionally, it doesn't respond well to initial treatment (**refractory** lymphoma).

If NLPHL comes back, you might have the same symptoms you had before or you might have different symptoms. If your medical team suspects your lymphoma has come back, they are likely to recommend that you have more scans and another biopsy to make sure it hasn't changed (**transformed**) to a faster-growing type of lymphoma.

Relapsed NLPHL usually responds very well to treatment.

Your medical team might recommend:

- active monitoring (page 38) if your lymphoma isn't causing any problems
- radiotherapy (page 40) if the lymphoma is only in one part of your body
- immunochemotherapy (page 42), usually with different drugs if you have had it before
- rituximab on its own, if you are not well enough to have chemotherapy
- high-dose chemotherapy with a stem cell transplant, if your lymphoma comes back very soon after treatment, comes back several times, or transforms to a high-grade lymphoma. This is a very intensive treatment and you have to be fit enough to have it. Most people with NLPHL do not need a stem cell transplant.

“

A PET scan showed the lymphoma had returned in the same position as before – in my armpit, chest, collarbone and stomach. A biopsy confirmed the return of NLPHL and I was put onto active monitoring. It hasn't stopped me from doing anything – I have continued to work, travel and stay active. I have checkups every three months and am currently well and stable.



Adam, diagnosed with NLPHL

Summary

- Your treatment will be planned by a multidisciplinary team, taking into account your individual needs.
- Treatment for NLPHL depends on the stage of your lymphoma and how it is affecting you.
- If NLPHL is only affecting one or two areas of your body, treatment might involve surgery or radiotherapy.
- If NLPHL is not causing any problems you might not need treatment straightaway. Instead, your medical team might recommend active monitoring.
- If your NLPHL is more advanced and needs treatment, you are likely to have immunochemotherapy (chemotherapy combined with the antibody treatment, rituximab).



“ I started to lose my eyebrows and leg hair but was glad that my hair and beard didn't fall out completely. The things that were the most problematic for me were constipation and insomnia.

Adam, diagnosed with NLPHL

Side effects

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Common side effects

Treatment aims to destroy lymphoma cells, but it can also damage healthy cells, causing unwanted side effects.

Your medical team can give you information about any side effects you might experience. They base this on lots of factors, including the type of treatment you have, how much of it, and how often, as well as 'individual factors', such as your age.

Usually, side effects are short-term and start to go away once you finish treatment. However, they can have a significant impact on your day-to-day life, including your emotional wellbeing.

Some of the common side effects of treatment include:

- **Fatigue.** Extreme tiredness that can be physical, mental or emotional. This can be worsened by the emotional impact of living with lymphoma.
- **Hair loss.** Some people experience hair loss or thinning. This can happen to the hair on your head, as well as elsewhere on your body.
- **Low blood counts and risk of infection.** Treatment can have a short-term effect on the number of blood cells you have. This can lead to **anaemia**, **thrombocytopenia** and **neutropenia** (pages 54-57).
- **'Chemo brain'.** Cancer-related cognitive impairment can affect thinking processes such as memory and attention. Some people describe this as a 'mental fog'. You might find it difficult to plan, keep up with a conversation or remember things.

- **Sickness.** Nausea (feeling sick) and vomiting (being sick) are common side-effects. There are effective anti-sickness medicines (antiemetics) that can help.
- **Nerve damage (peripheral neuropathy).** Damage to the nerves of the peripheral nervous system (network of nerves outside of the brain and spinal cord) can cause symptoms such as increased or decreased sensitivity to touch and temperature, and numbness and tingling (pins and needles) in your hands and feet.
- **Bowel problems.** This includes diarrhoea, constipation and wind (flatulence).
- **Skin problems and irritations.** You might get dry, sore and itchy skin in some areas of your body.
- **Sore mouth (oral mucositis).** This can cause symptoms such as pain when you swallow, mouth sores (ulcers) that can lead to infection, and dry, sore mouth and lips.
- **Reduced fertility.** Your doctors should talk to you about whether your lymphoma treatment is likely to affect your fertility. In general, fertility preservation is more effective if you take measures early, so it's a good idea to talk to your medical team about your fertility before you begin treatment.

“ *I had to plan my weeks carefully, the day after chemotherapy I felt so ill I couldn't do anything. It wasn't until the second week that I felt well enough to do things.*

Samantha, diagnosed with NLPHL



You can find out more about the potential side effects of lymphoma treatments and find tips to help live well with them at lymphoma-action.org.uk/SideEffects

Low blood counts

Treatment for lymphoma can temporarily damage your bone marrow. Your bone marrow makes your body's blood cells.

It is common to have low blood counts during your treatment. Your medical team regularly check your blood counts and make any adjustments to your treatment plan as necessary.

Neutropenia (low white blood cell count)

Having a low neutrophil (a type of white blood cell) count doesn't usually cause any symptoms but it means you have a higher risk of infection than normal. If you do get an infection, it can be serious, sometimes even life-threatening. An infection in someone with **neutropenia** needs urgent treatment. You usually have to stay in hospital for intravenous (IV) antibiotics and careful monitoring.

Possible symptoms and signs of infection include, but are not limited to:

- fever (temperature above 38°C/100.4°F)
- hypothermia (temperature below 35°C/95°F)
- shivering (even if you do not have a fever, which is more likely if you're taking steroid medication)
- chills and sweating
- feeling generally unwell, confused or disoriented
- blocked nose, earache, sore throat or mouth
- cough, yellow or green phlegm or snot (mucus), difficulty breathing
- redness and/or swelling of the skin, pain and redness around intravenous (IV) lines
- diarrhoea or vomiting
- a feeling of burning or stinging when you wee, or needing to wee more often than usual
- vaginal discharge or itching
- unusual and new stiffness of the neck with discomfort around bright lights
- new and increasing pain.

Contact your medical team if you have any of these signs or symptoms, no matter how minor they might seem.

“

I developed neutropenic sepsis and needed to be treated with antibiotics and growth factor injections to help my neutrophil count recover faster. I was in hospital for a week and my next chemotherapy was delayed.

Adam, diagnosed with NLPHL



Anaemia (low red blood cell count)

If you have a low red blood cell count, you don't have enough haemoglobin (the protein that carries oxygen around your body). This is called **anaemia**. It might make you feel tired or short of breath. If your red blood cell count is very low, you might need treatment with a blood transfusion – a drip (infusion) of donated blood or blood products given into one of your veins.

Tell your doctor if you feel short of breath, unusually tired, dizzy or have new aches and pains. This could be a sign of anaemia that needs treatment.

Thrombocytopenia (low platelet count)

Thrombocytopenia is a shortage of platelets. You might bruise easily, bleed more or bleed for longer than usual if you hurt yourself if you are thrombocytopenic.

Thrombocytopenia often gets better on its own quite quickly. However, if your platelet count is very low, or you are at particular risk of bleeding, your medical team might adjust your treatment or offer treatments to help your blood clot. In some cases, a transfusion of platelets is needed.

Possible symptoms and signs of thrombocytopenia include:

- nosebleeds
- bleeding gums after brushing your teeth
- heavier or longer periods than is usual for you
- bleeding for longer than you'd expect after a cut or scratch
- bruising more easily than usual
- red or purple patches or spots called 'purpura' or 'petechiae' on your skin (often on your legs), your lips or in your mouth
- blood in your sick
- blood in your wee
- blood in your poo (this might be obvious, bright red blood or it can make your poo black and sticky)
- persistent headache, blurred vision or a change in your level of consciousness.

Contact your medical team if you develop any of these symptoms.

If you have a low platelet count, take precautions to reduce your risk of bleeding. For example, avoid contact sports (such as rugby) and high-impact sports (such as football and martial arts). Wear gloves to protect yourself from injury while doing activities such as gardening, DIY and crafts such as sewing.

Managing side effects and symptoms

Speak to your medical team for advice about how to manage any side effects or symptoms you experience. Your medical team can offer suggestions about how to cope and might also offer suitable prescriptions to help.

For example, you might be offered:

- anti-sickness drugs (antiemetics)
- painkillers
- antibiotics
- steroids
- growth factors.

In some cases, you might also be offered a referral to a specialist who can offer further support.



Visit our website for top tips on how to manage the symptoms of lymphoma and the side effects of treatment, from people with a lived experience:
lymphoma-action.org.uk/TopTips

If you have low white blood cell counts (page 54) you should consider ways to reduce your risk of picking up any infections.

Tips to help lower your risk of infection

Keep good personal hygiene

- Wash your hands before eating and after using the toilet. Take antibacterial hand sanitiser gel or wipes with you if you are out and about.
- Have a warm bath or shower each day. Check with your medical team for advice about bathing and showering if you have a chemotherapy central line (central venous catheter) in place.
- Keep good dental hygiene. Use a soft toothbrush and an alcohol-free antiseptic/antibacterial mouthwash.

Minimise contact with germs

- Avoid places where you have a higher risk of catching an infection, such as swimming pools, busy shops and public transport at peak times.
- Avoid contact with people who are unwell, for example with a cold, tummy bug or chickenpox.
- Prepare food safely and don't eat anything that is past its sell-by-date – use refrigerated food within 24 hours of opening. You can find out more about food safety on the World Health Organization (WHO) website and the Food Standards Agency website.
- Take care when handling pets – avoid bites or scratches and wash your hands after any contact with an animal. If possible, ask someone else to deal with pet care jobs that involve animal poo, such as cleaning out litter trays.

- Visit your dentist before you start treatment for lymphoma – you might not be able to have any dental work done during or soon after treatment because of increased risk of infection.

Protect your skin

- Protect yourself from cuts and scratches by wearing gloves for gardening, wearing shoes when you are outside and avoiding walking barefoot indoors.
- Keep your skin moisturised with a body lotion or moisturiser if it becomes dry or cracked.
- Allow spots and scabs to heal without picking at them.

Summary

- Treatment destroys lymphoma cells but it can also damage healthy cells, causing side effects.
- Side effects usually go away in time.
- Different factors affect which side effects you have, including the treatment types you have, how much and how often.
- Talk to your medical team about any side effects you experience so that they can offer support and advice to help you to manage them.



Notes



“ *I have mixed emotions about being discharged, as I feel that the regular contact with my medical team is like a safety net. They explained that if I have any concerns, I can just call them, which I have found reassuring.*

Samantha, diagnosed with NLPHL

After treatment

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Follow-up

After finishing treatment for lymphoma, your medical team are there to support you in your physical and emotional recovery.

End-of-treatment appointment

You will have an end-of-treatment appointment with a member of your medical team.

You usually have a scan at the end of your treatment to check how well your lymphoma has responded. You might also be examined and have blood tests.

You'll be asked about your health and wellbeing, for example, about how you're feeling, any symptoms you have and how you're adjusting to life after treatment. This appointment is also a chance to ask any questions you might have about your lymphoma and the impact it has on your life.

Together, you and your medical team put together a care and support plan that is specific to your individual needs.

As well as the support your medical team offer, there is other support available. For example, we have a peer-led self-management Live your Life programme. Find out more at lymphoma-action.org.uk/LyL

During your follow-up period

Your follow-up appointments might be in person, over the phone or by video call. The aims are to check:

- your recovery from treatment
- for any signs that your lymphoma has come back (**relapsed**)
- for any **late effects** (page 70).

Most hospitals offer follow-up appointments for at least 2 years after you finish treatment. This is an important time in terms of your recovery from treatment and is the time when risk of relapse is higher. As NLPHL is a low-grade lymphoma, your follow-up appointments might continue for many years.

You usually have check-ups every 3 to 4 months at first, then every 6 months. If it is suitable for you, you might be offered a supported self-management system, although this isn't available at all hospitals. The idea is that you are supported to develop the skills, knowledge and confidence to book your own follow-up appointments, as-and-when you feel you need one.

You can contact your medical team at any time. Don't wait until your next appointment is due if you are worried.

After your follow-up period

Depending on the usual practice of your hospital, you might be referred back to your GP for health checks after a certain number of years in remission. Your GP usually becomes your main point of contact if you have any concerns or notice any new symptoms. Most hospitals also offer a phone number

to call if you have any concerns about relapse. If you are not given this information, ask for it.

Your GP should have a record of your diagnosis and all the treatment you've had. However, it's a good idea to remind them that you have had treatment for lymphoma. You should also tell any health professional who treats you in the future, including your dentist.

Feelings and emotions

Finishing treatment for lymphoma can bring a range of emotions. Some of these are likely to be positive but others might be harder to cope with. There is no right or wrong way to feel. You might feel differently at different times.

Many people miss the reassurance of frequent contact with their medical team after treatment. You might worry about the future and any changes you need to make to your plans. It can be an added difficulty if friends and family expect you to feel happy – for some people, this leads to feeling irritated and isolated, as though those around them don't understand that this continues to be a challenging time.

Talking to someone about how you feel can help you to make sense of challenging feelings.

If you'd like to talk about how you're feeling, call our Helpline freephone on 0808 808 5555, 10am to 3pm, Monday to Friday. Find out more about how we can support you on page 78.

You can consider getting support from a counsellor. Speak to your medical team if you're interested as they might be able to offer you a referral on the NHS. You can also search for a private therapist using the British Association of Counsellors and Psychotherapists online tool at bacp.co.uk/search/Therapists

“ My therapist is a massive part of my journey. He makes me feel positive on every visit and really listens to how I am feeling. It can be difficult talking to family and friends as I don't want to make them concerned, so it's good talking to someone who isn't emotionally attached.

Sophie, diagnosed with NLPHL



Healthy living and day-to-day life

Following a healthy lifestyle puts you in the best position to live well, with and beyond lymphoma. This includes:

- eating a healthy, balanced diet
- getting regular physical activity
- being a healthy weight
- not smoking
- limiting alcohol intake
- getting enough sleep
- managing stress
- protecting yourself from the sun
- keeping up-to-date with any vaccinations your medical team recommend
- taking up any screening programme checks you're invited to.

Your medical team can also tell you about any late effects to be aware of (page 70) and give you advice about other aspects of your life, such as safety precautions to take if you travel to another country.

We have more information about these lifestyle factors on our website and in our book *Living with and beyond lymphoma*

You might need to make some short-term or longer-term changes in your day-to-day life. For example, with practicalities such as work, studying and social activities. Your medical team should support you in finding ways to manage these aspects of your life.

Your employer must, by law, make any 'reasonable adjustments' that allow you to continue working during and after your treatment. Under the Equality Act 2010, this applies forever, not just while you are having treatment or for a limited time after finishing.



Search 'day-to-day' on our website for more information about where to find support with practicalities.

“ *I take one day at a time and try to enjoy life to the fullest. As I am on active monitoring, we try to do a lot of positive things as this diagnosis has been a reminder of how short life is. We have booked our wedding for next year, so really have got a lot to look forward to.*



Sophie, diagnosed with NLPHL

There is also a range of possible sources of support available to people who are looking after a family member or friend who has lymphoma.

If someone close to you has lymphoma, we have information for you on our website. We also have a book, *When someone close to you has lymphoma*, which offers practical tips and emotional support.

Late effects of treatment

Late effects are health problems that develop months or years after treatment for lymphoma. Your medical team should talk to you about the possible late effects of your treatment before it starts.

While it's not possible to say for certain whether you'll develop late effects, your medical team can give you an idea based on the treatment you've had and individual risk factors, such as your age and lifestyle.

You can't always prevent late effects. However, noticing problems early gives you a better chance of treating or managing them effectively if they do arise.

We outline some of the possible late effects of treatment below.



You'll find more information on our website at lymphoma-action.org.uk/LateEffects

Lung problems

Some treatments for lymphoma can cause scarring of your lungs (pulmonary fibrosis). This can happen with radiotherapy to the chest and with the chemotherapy drug bleomycin.

You are more likely to develop lung problems after lymphoma treatment if you smoke. If you smoke and would like free support to help you stop, talk to your GP or visit nhs.uk/smokefree

Heart problems

Radiotherapy to your chest and some chemotherapy drugs can damage your heart. This includes doxorubicin, a component of the ABVD and AVD, **regimens** commonly used to treat NLPHL.

Heart problems generally don't start until at least 10 years after treatment, but they can develop sooner.

You can lower your risk of developing heart problems by not smoking, maintaining a healthy weight, eating well and staying active. You should have your blood pressure, blood sugar level and cholesterol level checked regularly. Ask your GP surgery for information about how to book these.

Other cancers

Treatment for lymphoma can increase your risk of developing another cancer in the future. The type of cancer you might be at risk of depends on the exact treatment you had, the dose you had, how old you were when you were treated and how old you are now.

Ask your medical team what cancers you might be at higher risk of developing. Make sure you know the symptoms. Cancer is usually more treatable if it is diagnosed early.

Lifestyle can be a significant protective or risk factor, so take steps to follow a healthy lifestyle (page 68). You can also ask your medical team about any screening programmes you should be aware of.

If you are a woman who had radiotherapy to the chest area under the age of 36, you are likely to be referred for annual breast screening starting 8 years after treatment. Talk to your medical team if you think this applies to you.

Hormone problems

Treatment for lymphoma can affect the production of chemical messengers (hormones) in your body.

If you've had radiotherapy to the neck or upper chest, you might develop an underactive thyroid (hypothyroidism). This is where your thyroid gland makes less of the hormone thyroxine than it should. Thyroxine controls how your body uses energy. If you have too little of it, you might feel tired, sensitive to the cold and constipated. You might also gain weight easily. The risk of developing hypothyroidism is highest within the first 5 years of having treatment.

Some treatments for lymphoma can affect women's ovaries and men's testicles, leading to reduced fertility. This can happen with radiotherapy given to your tummy (abdomen) area or to the area below your belly button (pelvis). It can also happen with chemotherapy. Less is known about the effects of newer, targeted treatments. In women, treatment can also lead to an early menopause.

Summary

- After treatment, you have a follow-up period. This is to check your recovery and to help you manage any side effects or late effects of treatment. It also gives you a chance to talk to your medical team about questions or concerns you might have.
- Many people feel a wide range of emotions when they finish treatment. There is support available to help you through this time.
- A healthy lifestyle can help in your recovery and to live well, with and beyond lymphoma.
- After treatment, you might need to make some short or longer-term adjustments to your day-to-day life. This might include to your work or studies.
- Late effects are health problems that can develop months or years after treatment. Your medical team should talk to you before you begin treatment about any you might experience.

Glossary

Anaemia	shortage of haemoglobin (or red blood cells) in your blood stream
Anaesthetic	drugs given to make a part of the body numb (local anaesthetic) or put your whole body into a sleep-like state (general anaesthetic)
Antibody	a specialised protein made by white blood cells that helps to fight infections by sticking to proteins on the surface of cells that don't belong in your body
B symptoms	a set of symptoms: fever, drenching sweats and unexplained weight loss
Biopsy	a biopsy looks at a sample of cells under a microscope to check for lymphoma cells
Bone marrow	the spongy material at the centre of larger bones
Chemotherapy	treatment with anti-cancer drugs
Clinical nurse specialist (CNS)	a nurse who specialises in looking after people with lymphoma. They are usually your key worker

CT scan	computed tomography scan: uses X-rays to take pictures or 'slices' through your body
Cycle	a round of treatment followed by a rest period to give you time to recover before the next round of treatment
Diffuse large B-cell lymphoma (DLBCL)	a type of high-grade (fast growing) non-Hodgkin lymphoma
Immune system	the system in your body that fights off and prevents infection
Intravenous (IV)	into a vein
Late effects	health problems that develop months or years after treatment has ended
Lymphatic system	part of your immune system, the lymphatic system is a network of tubes, nodes and organs that filters out germs and toxins, helps destroy cells that are old or damaged and drains waste fluids from your tissues
Lymph nodes	small, oval swellings (glands) that are spread throughout your lymphatic system; they help your body fight infections and drain away waste fluids from tissues

Lymphocytes	a type of cell that grows out of control if you have lymphoma. There are three main types of lymphocyte – B cells, T cells and natural killer cells
MRI scan	magnetic resonance imaging: a scan that uses magnetic waves to take pictures of the inside of your body
Multidisciplinary team (MDT)	group of health professionals who meet to plan and manage your care and treatment according to your individual needs and preferences
Neutropenia	low levels of neutrophils (a kind of white blood cell) in the blood; can result in the body allowing infections to develop
PET scan	positron-emission tomography: a scan that uses a radioactive form of sugar to look at how active cells are
PET/CT scan	a test that combines a PET scan and a CT scan
Radiotherapy	a type of treatment for lymphoma that uses radiation to destroy cancer cells
Refractory	lymphoma that does not respond well to the first choice of treatment
Regimen	a treatment plan

Relapse	lymphoma that comes back after successful treatment and a period of remission
Remission	no evidence of lymphoma in tests or scans
Spleen	an organ that filters blood
Stage	a measure of how much of your body is affected by lymphoma
Stem cell transplant	a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells
Thrombocytopenia	a shortage of platelets in the blood that increases the likelihood of bruising and/or bleeding
Thymus	a small gland behind your breastbone where some of your immune cells develop
Ultrasound scan	a scan that uses high-energy soundwaves to take pictures of the inside of your body
White blood cell	a cell found in the blood and in many other tissues that helps our bodies to fight infections. There are several different types, including lymphocytes and neutrophils

Information and support

If you or someone you love is affected by lymphoma, we're here to support you. We have a range of support services that are free to access. Find out more at lymphoma-action.org.uk/support-you



Helpline: a freephone helpline available Monday to Friday, 10am to 3pm on 0808 808 5555, or use Live Chat on our website



Online Support Meetings: a safe place to connect with others affected by lymphoma



Facebook Support Group: our UK-wide group is for anyone affected by lymphoma



Buddy Service: peer support from someone with similar lived-experience of lymphoma



Preparing for Treatment Service: online support and information to help you prepare for treatment.

For our latest news and updates, follow us on social media:

  @lymphomaaction    lymphoma_action

If you're interested in finding out more about lymphoma, we have lots more information on our website, including videos and podcasts.

We also produce a number of books, which are available free of charge, including:

- *Introduction to lymphoma*
- *Young person's guide to lymphoma*
- *Active monitoring*
- *Living with and beyond lymphoma*
- *When someone close to you has lymphoma*
- Easy Read books.

Find our full range of books and information at lymphoma-action.org.uk/Books or call us on 0808 808 5555.

Our information is evidence-based, approved by experts and reviewed by users. We have been awarded the PIF TICK – the UK's only assessed quality mark for printed and online health and care information. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo



Useful organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites. If you don't find what you are looking for, please contact our Helpline (page 78).

British Association for Counselling and Psychotherapy provides a list of accredited counsellors in your area.

Cancer Research UK has information on all types of cancer and a nurse-led helpline: 0800 800 4040.

Carers UK offers advice, information and support for carers.

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.

Maggie's provides practical, emotional and social support to people with cancer and their family and friends.

Mind offers support and advice to anyone experiencing a mental health problem.

Teenage Cancer Trust provides cancer services and support for young people affected by cancer.

Young Lives vs Cancer provides emotional and practical support for young people with cancer and their families.



Visit lymphoma-action.org.uk/UsefulOrgs for a list of other organisations you might find helpful

How you can help us

Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

We continually strive to improve our resources and are interested in any feedback you might have. Can you spare five minutes to give feedback on this book? It will help us plan future versions. Please scan the QR code to complete our short survey. Alternatively, please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support Team on 0808 808 5555.



References

The full list of references for this book is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

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This book has been researched and written by Lymphoma Action, the UK's leading charity dedicated to supporting people affected by lymphoma.

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This book describes what nodular lymphocyte predominant Hodgkin lymphoma is, how it typically affects people, how it is treated, and what to expect after treatment.

Lymphoma Action is a charity that has been providing trusted information and support to people affected by lymphoma since 1986.

We're here for you.



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