Low-grade non-Hodgkin lymphoma

- Follicular lymphoma
- Mantle cell lymphoma
- Marginal zone lymphomas
- Lymphoplasmacytic lymphoma
- Waldenström’s macroglobulinaemia
This book has been researched and written for you by Lymphoma Action, the only UK charity dedicated to people affected by lymphoma.

We could not continue to support you, your clinical team and the wider lymphoma community, without the generous donations of our incredible supporters. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued.

To make a donation towards our work, please visit lymphoma-action.org.uk/Donate
Your lymphoma type and stage

Your treatment

**Key contact**

Name: ________________________________

Role: ________________________________

Contact details: ________________________________

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<td>Clinical nurse specialist or key worker</td>
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Low-grade (or indolent) non-Hodgkin lymphoma is a type of blood cancer that develops from white blood cells called lymphocytes. It is a broad term that includes lots of different types of lymphoma.

This book explains what low-grade non-Hodgkin lymphoma is and how it is diagnosed and treated. It includes tips on coping with treatment and dealing with day-to-day life.

The book is split into chapters. You can dip in and out of it and read the sections that are relevant to you at any given time.

Important and summary points are written in the chapter colour.

- Lists practical tips and chapter summaries.
- Gives space for questions and notes.
- Lists other resources you might find useful, some of which are online. If you do not have internet access, please contact our helpline (see page 159).

This book uses some scientific words. Words that are in **bold** are explained in the glossary on pages 154 to 158.

Special thanks to Andy, Carole, Caroline, Christine, Debbie, Douglas, Jackie, Julia, Julian, Lesley, Malcolm, Pat, Peter, Stephen, Sue, Sue and Trevor for sharing their experiences. Quotations from their stories are featured throughout the book.
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I felt numb but not surprised when I was diagnosed. No amount of preparation for the news actually helped. I knew there were many questions I needed to ask, and yet, in that instant, I could not think of a single one.

Julian, diagnosed with nodal marginal zone lymphoma, age 66
Introduction to lymphoma

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Making informed choices

You might find it useful to learn about your type of lymphoma and the possible treatment options you might have. This could help you:

• make decisions about your health and wellbeing
• manage any fears and anxieties you might have
• recognise when to contact your medical team
• cope with side effects
• lower your risk of developing late effects
• feel more in control of what is happening to you.

“After my diagnosis, I started doing all the things you never get around to, and accomplished far more than I would have done otherwise. Maybe it was being busy that helped me come to terms with the lymphoma, but all I could do was deal with it in the best way for me.

Pat, diagnosed with follicular lymphoma, age 56
What is lymphoma?

Lymphoma is a type of blood cancer that develops when white blood cells called lymphocytes grow out of control. They divide in an abnormal way or do not die when they should.

Lymphocytes travel around your body in your lymphatic system, helping you fight infections. If you have lymphoma, abnormal lymphocytes build up in your lymphatic system, often in lymph nodes that you might be able to see or feel in your armpits, neck or groin.

Lymphoma is the fifth most common type of cancer in the UK. Each year, almost 20,000 people are diagnosed with lymphoma in the UK.

Lymphoma is nearly always treatable.

What is the lymphatic system?

Your lymphatic system is part of your immune system, which helps protect you from infection. It runs throughout your body, carrying a fluid called lymph.

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

It protects your body by filtering out germs and toxins (poisons) and helping to destroy cells that are old, damaged or abnormal. It also drains waste fluids from your tissues.
You have lymph nodes and lymph vessels throughout your body. Some lymph nodes are easy to feel, such as in the neck, under the arms and in your groin. Others are deeper inside the body where they’re harder to feel.

**How does lymphoma develop?**

Most of the cells in your body are dividing all the time to make new cells. These replace old cells that die off naturally. Usually, cell division and cell death are kept carefully in balance so you only make the number of new cells your body needs.

Lymphoma occurs when this carefully controlled system breaks down. Instead of dying as they should, some lymphocytes divide in an uncontrolled way. These abnormal lymphocytes collect together to form a lump. This lump is lymphoma. It usually develops in a lymph node but it can develop in almost any part of your body, such as the spleen, liver or **bone marrow**.

![Figure: How cancer develops](image)
Types of lymphoma

There are over 60 different types of lymphoma. They are broadly grouped into Hodgkin lymphoma and non-Hodgkin lymphoma, depending on what they look like under a microscope.

- Hodgkin lymphoma contains large abnormal cells called Reed–Sternberg cells.
- Non-Hodgkin lymphoma is any lymphoma that is not Hodgkin lymphoma.

There are many different types of non-Hodgkin lymphoma. Different types of lymphoma behave differently and need different treatment.

“I had no idea what follicular lymphoma was. I was in proper panic mode - fearful and horrified. My wife, Brenda, found out as much information as she could from Lymphoma Action, and in fact we were given one of the charity’s leaflets at the hospital when I was diagnosed. But it was really hard for me to take in information at that point. Your brain’s still in shock I think.”
Malcolm, diagnosed with follicular lymphoma in 2007
Summary

- Lymphoma is a type of blood cancer.
- Lymphoma develops when white blood cells called lymphocytes grow out of control.
- There are over 60 different types of lymphoma. They are broadly grouped into Hodgkin lymphoma or non-Hodgkin lymphoma.
I had no idea that anything was wrong with me. I was a regular runner, fit and healthy, or so I thought. So to get a diagnosis completely floored me.

Julia, diagnosed with follicular lymphoma, age 47
Low-grade non-Hodgkin lymphoma

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What is the outlook? 23
What is low-grade non-Hodgkin lymphoma?

There are two main ways to group non-Hodgkin lymphomas, based on:

- how fast the lymphoma cells are growing
- the type of lymphocyte they developed from.

Low-grade or high-grade lymphoma

Lymphoma cells can grow slowly or quickly.

Non-Hodgkin lymphomas that grow slowly are called low-grade (or indolent) non-Hodgkin lymphomas.

Non-Hodgkin lymphomas that grow quickly are called high-grade (or aggressive) non-Hodgkin lymphomas.

B-cell or T-cell lymphoma

There are two main types of lymphocyte: B lymphocytes (B cells) and T lymphocytes (T cells). They work in different ways to protect your body from infection and illness.

- T cells recognise and stick to germs (especially viruses) or cancer cells. They either kill the cell directly, or activate other parts of your immune system to kill it.
• B cells make antibodies that stick to proteins on the surface of cells that don’t belong in your body, such as viruses, bacteria or cancer cells. The antibodies can either kill the cell directly, or act like a flag that attracts other immune cells to destroy it.

Either of these types of lymphocyte can grow out of control and cause lymphoma to develop.

• Non-Hodgkin lymphomas that develop from B cells are called B-cell lymphomas. Most lymphomas are B-cell lymphomas.
• Non-Hodgkin lymphomas that develop from T cells are called T-cell lymphomas. They are usually high-grade lymphomas.

There are many types of lymphoma in each of these main groups. Each type behaves differently and might need different treatment.

There is more information on the different types of low-grade non-Hodgkin lymphoma in the last chapter of this book (pages 143 to 153).

Ask your medical team if you’re not sure what type of lymphoma you have.
Who gets low-grade non-Hodgkin lymphoma?

Over 14,000 people are diagnosed with non-Hodgkin lymphoma each year in the UK – around 38 people every day. Just under half of these people have low-grade non-Hodgkin lymphoma. In addition, almost 4,000 people each year are diagnosed with chronic lymphocytic leukaemia (CLL), which is sometimes considered a form of non-Hodgkin lymphoma.

Most people who are diagnosed with non-Hodgkin lymphoma are over 55, but it can affect people of any age. However, it most commonly develops in people aged between 60 and 90.

Non-Hodgkin lymphoma affects slightly more men than women. It can develop in people of any ethnic background.

We produce a separate book about chronic lymphocytic leukaemia (CLL). Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.
What causes low-grade non-Hodgkin lymphoma?

Scientists don’t know exactly what causes lymphoma, but they do know that:

• it is not caused by anything you have done
• you can’t catch it from anyone
• you can’t pass it on to anybody else
• it isn’t inherited.

Unlike many other types of cancer, lifestyle factors don’t have much impact on your risk of developing lymphoma. Anyone can develop lymphoma but your risk is higher if you have problems with your immune system. For example, people who have autoimmune conditions (when your immune system mistakenly attacks your own body) are more likely to develop lymphoma than other people. However, most people who have autoimmune conditions do not develop lymphoma.

Some types of lymphoma are linked to infections with certain viruses or bacteria.
What are the symptoms of low-grade non-Hodgkin lymphoma?

Low-grade non-Hodgkin lymphoma can cause a variety of symptoms depending on where in your body it develops. Most people have a mixture of symptoms. Even people with the same type of lymphoma can have different symptoms.

People with low-grade non-Hodgkin lymphoma often have mild symptoms. Some people might not have any symptoms, and might be diagnosed during tests for something else.

Swollen lymph nodes

The most common symptom of lymphoma is a swollen lymph node or nodes that do not go down after a couple of weeks. The swollen lymph nodes are not usually painful and have a ‘rubbery’ texture. They typically develop in the neck, armpit or groin. They can also develop deep inside your body where you can’t feel them from the outside.

It is important to remember that lymph nodes can swell for lots of reasons (for example, if you have an infection). Most people with swollen lymph nodes do not have lymphoma.
B symptoms

Some people with low-grade non-Hodgkin lymphoma have symptoms known as ‘B symptoms’. These are one or more of the following:

- **Fever**: a high temperature (above 38°C) that might come and go.

- **Drenching sweats**: especially at night.

- **Unexplained weight loss**: losing weight quickly without trying to.
Other symptoms

Some people with lymphoma have other symptoms, such as:

- **Fatigue**: feeling exhausted or washed out after doing very little. Fatigue is caused by a combination of the lymphoma cells using up energy, the emotional impact of having lymphoma, and factors such as disturbed sleep. Cancer treatment can also make you tired.
- **Difficulty shaking off infections**: your body is making abnormal lymphocytes, so there might not be enough normal lymphocytes left to fight infections.
- **Itching**: which might be worse in hot weather or at night. Scientists think it is caused by chemicals released by your immune system as it tries to fight off the lymphoma.
- **Poor appetite**: you might not feel like eating much, or you might feel full after eating only a small amount.

Extranodal symptoms

Sometimes, lymphoma develops outside the lymph nodes. This is called ‘extranodal’ lymphoma. For example, it might develop in your gut, liver, lungs, skin, bone marrow or brain. The symptoms you might get depend on where the lymphoma is.
Symptoms of extranodal lymphoma can include:

- tummy pain or back pain
- diarrhoea, constipation or bloating
- a persistent cough or breathlessness
- a rash
- a tendency to bruise or bleed easily.

**What is the outlook for people with low-grade non-Hodgkin lymphoma?**

Low-grade non-Hodgkin lymphoma is likely to respond well to treatment and often goes into remission. However, it usually returns at some point because the slow-growing cells in low-grade lymphomas are hard to get rid of completely. Depending on your symptoms when it returns, you might need further treatment.

Low-grade lymphoma is usually treated with the aim of reducing the lymphoma and any symptoms you have as much as possible. This is sometimes called ‘managing’ or ‘controlling’ the lymphoma rather than curing it. However, if the lymphoma is only affecting one part of your body (localised lymphoma), it can sometimes be cured with radiotherapy.

Low-grade non-Hodgkin lymphoma can often be controlled for many years but it usually comes back (relapses) or gets worse (progresses) at some point. This might not be for many months or years.
Although a relapse can be very distressing, many people are treated successfully again. Most people with low-grade non-Hodgkin lymphoma have several different treatments over the course of their illness. It helps some people to think of it as a long-term (chronic) disease that needs treatment from time-to-time.

Your lymphoma specialist is the best person to talk to about the likely outcome of your treatment. They consider a range of factors, such as:

- your age
- the exact type of lymphoma you have
- how much lymphoma you have in your body and where it is (the *stage* of your lymphoma; page 36)
- the results of your tests and scans
- how well you are able to look after yourself and carry out normal day-to-day activities (known as your ‘performance status’)
- any other medical conditions you have.

We still have to wait and see what happens in the future and whether the lymphoma comes back, but for now it feels like we’ve all walked across burning coals and are on the other side.

Sue, whose husband Trevor was diagnosed with follicular lymphoma in 2012
Summary

- Low-grade non-Hodgkin lymphoma is a slow-growing type of lymphoma.
- It is more common in older people.
- Doctors don’t know exactly what causes it.
- Non-Hodgkin lymphoma can cause different symptoms depending on where it develops. Different people experience different symptoms.
- The most common symptom is a swollen lymph node or nodes, often in the neck, armpit or groin.
- Low-grade non-Hodgkin lymphoma is usually treated with the aim of controlling or managing the lymphoma, rather than curing it.
I noticed a dull ache in my groin and felt a lump. After tests, a haematologist told me I had follicular B-cell non-Hodgkin lymphoma, probably stage 3. A month before, I didn’t even know there was anything wrong with me, and now I am diagnosed with a stage 3 cancer. How does that work? 

Andy, diagnosed with follicular lymphoma in 2009
Tests, scans and staging

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How is low-grade non-Hodgkin lymphoma diagnosed?

Your GP is usually your first point of contact if you have symptoms of lymphoma. If your GP thinks you might have lymphoma, they will refer you for an urgent appointment with a hospital specialist.

The symptoms of lymphoma are more commonly seen in other, less serious illnesses, such as infections.

What tests might I need?

Your specialist is likely to send you for tests and scans to confirm whether or not you have lymphoma. If you do have lymphoma, you will need more tests to find out exactly what type of lymphoma you have and where it is in your body.

This section describes some common tests for lymphoma, but you might not need all of them.

For more information about any of the tests and scans described below, visit lymphoma-action.org.uk/Tests


Lymph node biopsy

A biopsy is the only way to tell for certain whether or not a lump is lymphoma. This means taking a sample from the lump (often a swollen lymph node) to be examined in a lab. Sometimes the whole lymph node is removed (an ‘excision’ biopsy) and sometimes just a core of tissue is removed. The exact procedure depends on where the lump is. It usually involves having a minor operation performed by a surgeon or a radiologist under a local anaesthetic. Most people go home the same day.

Arrange for somebody to drive you home after your biopsy.

Your biopsy sample is sent to a laboratory to be examined under a microscope and to have specialised tests to find out what type of lymphoma you have. This is done by a pathologist. Biopsy results usually take a week or more to come back. The results of more specialised tests can take longer.

Occasionally, the first biopsy does not give enough information to make a diagnosis and you need to have a second biopsy.
Blood tests

Blood tests can provide useful information about how your lymphoma is affecting your body. They are also used to check how your treatment is affecting you.

Scans

Scans are used to find out what parts of your body are affected by lymphoma. Some scans are better than others at assessing different parts of your body. Your medical team will tell you what scans you need and give you detailed information about them. We provide an overview of the more common scans here.

“My scan showed that the disease was confined to my neck, armpit and just above my collar bone. I was stage 2A with no symptoms and I was in good general health so my medical team recommended radiotherapy.

Julian, diagnosed with nodal marginal zone lymphoma, age 66

For more information about having scans, search for the name of the scan at nhs.uk
CT scans

Computed tomography (CT) scans use a series of X-rays to make detailed pictures of ‘slices’ through your body.

CT scans don’t hurt and only take about 15 minutes. You might have a ‘contrast’ injection to help certain parts of your body show up better. You have to lie still during the scan.

Figure: Having a CT scan

- Speak to a member of staff if you are anxious about having a CT scan.
- Tell someone if you feel hot or dizzy during your scan.
PET scans

Positron-emission tomography (PET) scans use a harmless radioactive form of sugar to look at how active the cells in your body are. More active cells, such as lymphoma cells, take up more sugar than less active cells. The radioactivity in the cells is detected with a special camera.

Most people with lymphoma have a PET scan to find out which parts of their body are affected by lymphoma. You might have another one at the end of any treatment you have, to check if it has worked.

A PET scan takes longer than a CT scan. First you have the radioactive sugar injected into a vein. You then rest for around an hour while the sugar travels throughout your body and is taken up by your cells. The PET scan itself takes 30 to 60 minutes. In some hospitals, you have a CT scan at the same time. This is known as a PET/CT scan.

- If you have diabetes, you need to fast before a PET scan to keep your blood sugar stable. Your medical team will tell you what you need to do to look after your diabetes on the day of your scan.
- Tell your medical team if you are worried about having a PET scan.
Ultrasound scans

Ultrasound scans use soundwaves to take pictures inside your body. They can be used to examine swollen lymph nodes that are near the surface of your skin. They can also help find the best place to take a biopsy (page 29).

Bone marrow biopsy

Bone marrow is the spongy tissue in the middle of your larger bones. It is where blood cells are made. Your bone marrow can be affected by lymphoma.

Your medical team looks at the results of your PET/CT scan and your blood tests to decide if you need a bone marrow biopsy. You are unlikely to have a bone marrow biopsy if your doctor feels it won’t alter the treatment they recommend.

A bone marrow biopsy usually involves taking a sample of bone marrow from your hip bone under a local anaesthetic.

Having a bone marrow biopsy can be uncomfortable but any pain or discomfort is usually brief. You might need painkillers before and after the procedure.
Questions to ask about tests and scans

• What tests do I need and why?
• Where and when will I have the tests?
• Will I need an anaesthetic?
• Do I need to do anything to prepare?
• Is there anything I need to be careful of afterwards?
• Can I drive? Can I go back to work straightaway?
• How long will it be before I get the results?
• Who will explain what the results mean?
Waiting for your test results

It is natural to feel anxious when you are waiting for tests and their results. Remember that it’s very important for your doctors to have all the information they need about your lymphoma so they can plan the most suitable treatment for you.

Talk to your medical team about how much information you want and how you’d like to be told. Would you like to know everything, or just the answers to specific questions? Are you happy for information to be shared with anybody else (for example, a family member)?

If you are finding it hard to cope with waiting for your test results, use our Helpline Services (see page 159 for details) or visit lymphoma-action.org.uk/Waiting for tips on how to cope.
Staging of non-Hodgkin lymphoma

‘Staging’ is the process of working out which parts of your body are affected by lymphoma (in other words, how ‘advanced’ your lymphoma is). There are four main stages of lymphoma. These are numbered 1 to 4, sometimes written in Roman numerals as I to IV.

**Stage 1 (I)**

You have lymphoma in only one **lymph node** or group of lymph nodes. This could be anywhere in your body.

**Stage 2 (II)**

You have lymphoma in two or more groups of lymph nodes but they are all on the same side of your diaphragm.*
The results of your tests and scans help doctors to work out the **stage** of your lymphoma. Staging lymphoma is important because it helps your medical team plan the most appropriate treatment for you.

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

**Stage 3 (III)**
You have lymphoma in lymph nodes on both sides of your diaphragm.*

**Stage 4 (IV)**
You have lymphoma in your **bone marrow** or in organs outside your **lymphatic system**.

* Your diaphragm is the muscle separating your chest from your tummy.
Sometimes letters are added to the stage.

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<td>A</td>
<td>You don’t have any <strong>B symptoms</strong>.</td>
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<tr>
<td>B</td>
<td>You have one or more B symptoms (weight loss, night sweats or fevers).</td>
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<tr>
<td>E</td>
<td>You have lymphoma that started outside the lymphatic system (‘extranodal’ lymphoma). Extranodal lymphoma doesn’t include lymphoma that started in a <strong>lymph node</strong> and spread to a body organ.</td>
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<tr>
<td>X</td>
<td>At least one of your affected lymph nodes is large or ‘bulky’.</td>
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**Early stage and advanced stage lymphoma**

Stage 1 or stage 2 lymphoma is known as ‘early stage’ disease. Stage 3 or stage 4 lymphoma is known as ‘advanced stage’ disease.

The lymphatic system is all over the body, so it is common for lymphoma to be advanced when it is diagnosed. However, it is generally sensitive to chemotherapy, which can reach cancer cells all over your body. **Unlike many other cancers, advanced stage lymphoma can be successfully treated.**

Ask your specialist if you’re not sure what stage your lymphoma is.
Grading of follicular lymphoma

If you have follicular lymphoma (page 145), your doctor might tell you the grade (1, 2, 3A or 3B) as well as the stage of your lymphoma. The grade relates to the number of large lymphocytes that the pathologist can see under a microscope. Grade 1 has the fewest and grade 3B has the most. Grades 1 and 2 are often grouped together as ‘grade 1 to 2’ follicular lymphoma.

Grades 1 to 2 and 3A follicular lymphoma are all slow-growing and are treated in the same way. The grade does not affect the likely outcome of treatment.

Grade 3B follicular lymphoma is usually fast-growing. Under a microscope, it looks like a type of high-grade non-Hodgkin lymphoma called diffuse large B-cell lymphoma (DLBCL). It is treated like a high-grade non-Hodgkin lymphoma.

Following a bone marrow biopsy, I was diagnosed with follicular lymphoma. I had never even heard these words before. For me, the really frightening thing was the word ‘cancer’.
Malcolm, diagnosed with follicular lymphoma, age 60

We produce a separate book about high-grade non-Hodgkin lymphoma. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.
Summary

• Low-grade non-Hodgkin lymphoma is usually diagnosed using a lymph node biopsy.
• You have other tests such as blood tests and a CT or 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 medical team plan the most suitable treatment for you.
My medical team were keeping an eye on me, but said I still didn’t need to start treatment. When my lymphoma progressed, my medical team talked about the different treatment options. Even though I had thought about this while I was on watch and wait, it still felt like I needed time to gather my thoughts and read information and decide the best way forward for me.

Lesley, diagnosed with follicular lymphoma in 2013
How is low-grade non-Hodgkin lymphoma treated?

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How is treatment organised?

Most people have one main consultant who is responsible for their care, usually either an oncologist (a doctor who specialises in treating people who have cancer) or a haematologist (a doctor who specialises in diseases of the blood, including blood cancers). The consultant works with a team of other health professionals. This is your multidisciplinary team or medical team. They meet regularly to discuss your treatment, taking your individual needs into account.

You usually have a named ‘key worker’ – a person you can call for advice or if you have any questions or worries about your lymphoma or your treatment. This is usually a clinical nurse specialist (a nurse who specialises in looking after people with lymphoma).

Make sure you have a name and contact details for your key worker. You can write these down in the front of this book.

Most people find it helpful to take a relative or friend with them to their hospital appointments. They might remember parts of the discussion that you don’t, or might think of other questions or concerns. Most doctors encourage people to bring someone along.
Where will I be treated?

You might have your treatment at your local hospital, or at a larger hospital with a cancer centre that could be further away. Sometimes people have their treatment shared between the two places.

Most people with low-grade non-Hodgkin lymphoma have treatment as an outpatient: you go to hospital on treatment days and go home afterwards. For some treatments, or if you develop side effects such as an infection or very low blood counts, you might have to stay in hospital.

Questions to ask your medical team

• Where will I be treated?
• Who will be involved in my care?
• How often will I have appointments?
• Does my hospital take part in clinical trials?
• What other experts are there to help if I need them? For example, can I meet with a dietitian or a physiotherapist?
• Does my hospital provide any extra support, such as counselling or complementary therapies?
• What facilities are there at my hospital?
• Will I have access to WiFi?
How does my medical team decide what treatment I need?

Your treatment is tailored to you. Your individual case is reviewed by several specialist lymphoma professionals at a multidisciplinary team meeting. Your medical team suggests the most appropriate treatment for you based on your test results and circumstances. They consider:

- the exact type of lymphoma you have
- where your lymphoma is growing
- how big the lumps of lymphoma are
- how the lymphoma is affecting you, including any symptoms you’re experiencing and the results of your blood tests
- your age
- other health conditions you have
- your general fitness
- how you feel about your treatment options
- other factors that might be important to you in the future, such as having a family.

If you don’t have symptoms, your medical team might not recommend treatment straightaway. Instead, you might be closely monitored (active monitoring or ‘watch and wait’; see page 58).

Let your medical team know if you have any strong views about your treatment.
Your team should also talk to you about your physical, emotional and social needs. This is called a ‘holistic needs assessment’ or HNA. Your team uses it to create a care and support plan that’s specific to you. You might have an HNA at key points in your treatment pathway, such as when you are first diagnosed and when you finish treatment.

If you’re pregnant when you are diagnosed, your medical team will take this into account when planning your treatment. Ask your medical team to guide you.

Visit lymphoma-action.org.uk/Pregnancy for more information about treatment during pregnancy.

Your doctors try to balance the chances of your lymphoma coming back against your risk of developing side effects and late effects (health problems that develop months or years after treatment).

It can be difficult to weigh up the benefits and risks of the possible treatment options. Talk it through with your medical team and, if you would like to, your family and friends. Ask as many questions as you need to help you make a decision.
Treatment options for low-grade non-Hodgkin lymphoma

Treatment for low-grade non-Hodgkin lymphoma is planned individually according to your particular circumstances. Even if you have the same type of lymphoma as someone else, you might not have the same treatment. However, in general:

- If your lymphoma isn’t causing serious health problems, you might not need treatment straightaway. Instead you might have active monitoring or ‘watch and wait’ (page 58).
- When treatment is needed, most people with low-grade non-Hodgkin lymphoma have chemotherapy combined with antibody therapy. This is called ‘chemo-immunotherapy’ (pages 72 and 116).
- Some people might have radiotherapy (page 75).
- For certain types of low-grade non-Hodgkin lymphoma, you might have a targeted therapy (page 73) or a stem cell transplant (page 78).

The next section summarises the most common treatment options for low-grade non-Hodgkin lymphoma. Treatment for particular types of non-Hodgkin lymphoma is outlined on pages 57 to 85.
Early stage low-grade non-Hodgkin lymphoma

If you have low-grade non-Hodgkin lymphoma that is only affecting one part of your body, you are likely to have radiotherapy to the affected area (page 75). In some cases, this can cure the lymphoma.

Sometimes radiotherapy is not suitable – for example, if your lymphoma is close to important organs that could be damaged by the radiotherapy, or if you have other medical conditions that make radiotherapy unsafe.

In this case, you are likely to be treated in the same way as people with advanced stage low-grade non-Hodgkin lymphoma.

Advanced stage low-grade non-Hodgkin lymphoma

Most people with low-grade non-Hodgkin lymphoma have advanced stage lymphoma when they are diagnosed. ‘Advanced’ doesn’t mean ‘untreatable’ – just that the lymphoma is affecting several groups of lymph nodes or several areas of the body.

Most people with advanced stage low-grade non-Hodgkin lymphoma live for many years with their lymphoma, needing treatment from time-to-time.
If you have advanced stage follicular lymphoma that is not causing troublesome symptoms, you might have:

- active monitoring (page 58) until you need treatment
- a short course of an antibody therapy (page 71), which can help to delay the need for more treatment.

Some types of low-grade non-Hodgkin lymphoma are linked to infections. In these cases, treating the infection with antibiotics or antiviral medicines can sometimes clear the lymphoma.

If your lymphoma is causing problems, your medical team are likely to recommend a course of chemotherapy combined with antibody therapy (page 72 and 116). This is known as ‘chemo immunotherapy’.

People with some types of low-grade lymphoma have a course of maintenance therapy after their initial treatment ends (page 81). This aims to keep the lymphoma under control for as long as possible. Maintenance therapy involves having an injection of antibody therapy every 2 months, usually for 2 years.

Read more about your particular type of lymphoma on pages 143 to 153.
More intensive treatments

Intensive treatments are sometimes used if a low-grade lymphoma comes back. They might also be used as initial treatment for mantle cell lymphoma (page 146). Mantle cell lymphoma is unlike other low-grade lymphomas. Although it sometimes grows slowly and is treated in a similar way to other low-grade lymphomas, it sometimes grows more rapidly and behaves like a high-grade lymphoma. If this is the case, it needs more intensive treatment.

If you need intensive chemotherapy, you are likely to stay in hospital to have your treatment and during your recovery period while your blood counts are low.

If you respond well to chemotherapy and you are well enough, your medical team might then recommend a stem cell transplant (page 78). A stem cell transplant could give you a better chance of staying in remission for longer.

Because I was in otherwise good health and fitness for my age, I was considered suitable for intensive treatment with chemo-immunotherapy followed by an autologous stem cell transplant.

Peter, diagnosed with mantle cell lymphoma in 2019, age 65
Research and clinical trials

Your medical team might ask you if you would like to take part in a clinical trial.

Clinical trials are medical research studies involving people. They are used to test new treatments or new ways of using existing treatments (for example, different combinations of chemotherapy drugs or lower doses of radiotherapy) to find out if they are better than standard treatment options.

Clinical trials are voluntary. You don’t have to take part in a trial even if you are offered one. You can choose to have standard treatment if you prefer.

If your medical team doesn’t suggest a clinical trial and you are interested in taking part in one, ask if there is one that is suitable for you. You might be able to be referred to another hospital if there is not a trial running at your hospital.

For more information about clinical trials, or to search for a trial that might be suitable for you, visit lymphoma-action.org.uk/Trialslink. We also produce a book about clinical trials. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.
Treatment for older people and people with other health conditions

Most people diagnosed with non-Hodgkin lymphoma are over 60. Age alone might not affect treatment but people over 60 are more likely to have other health conditions as well as lymphoma, and are generally more likely to experience more serious side effects than younger people. They are also likely to recover more slowly from side effects.

For example, if you have heart or lung problems, there are some chemotherapy drugs that might not be suitable for you. It could take your bone marrow longer to recover from chemotherapy than younger people. This could lead to low blood counts (page 90). You might also be more sensitive to the side effects of radiotherapy.

Your medical team always aims to give you a treatment that is as safe and effective as possible with the lowest possible risk of causing side effects. They will consider your fitness and any other health problems you might have. If they think you have a higher risk of side effects, they will talk to you about how they can adapt your treatment to suit your individual circumstances.
Your medical team might:

- recommend a gentler treatment option, avoiding drugs that are more likely to cause side effects
- give you a lower dose of some drugs
- reduce how often you have your treatment, giving your body longer to recover between each round of treatment.

Questions to ask about your treatment

- What treatment do you recommend for me? Why?
- What does the treatment involve?
- Where will I have my treatment? Do I need to come into hospital?
- When will my treatment start?
- How often will I have treatment?
- How long will each treatment session take?
- How many treatment sessions will I need?
- How will I know if the treatment has worked?
- How effective is this treatment? Will it cure the lymphoma?
- I have another illness – how will this affect my treatment?
- What happens if I decide I don’t want any treatment?
- Is there a clinical trial that is suitable for me?
Summary

• A ‘multidisciplinary team’ of health professionals is involved in your care. You might have a named key worker, who is your main contact.
• Your treatment is tailored to you, based on your test results and your individual circumstances.
• If your lymphoma isn’t causing serious health problems, you might not need treatment straightaway.
• Some people have radiotherapy for early stage lymphoma.
• Most people who need treatment for low-grade non-Hodgkin lymphoma have chemo-immunotherapy (chemotherapy combined with antibody therapy).
I was diagnosed with stage 4 follicular lymphoma and had six cycles of R-CHOP chemo-immunotherapy. I think I had prepared myself for a horrible experience, so, although I felt queasy at times, treatment wasn’t as bad as I had expected. I had been warned that I would lose my hair, but this wasn’t something I really worried about – in fact, I have more hair now that it has grown back than I did before.

Douglas, diagnosed with follicular lymphoma in 2010
Having treatment for low-grade non-Hodgkin lymphoma

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Active monitoring (‘watch and wait’)

For some types of low-grade non-Hodgkin lymphoma, 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, or that your doctors are trying to save money on your treatment. It means that, while you are well, you can avoid the side effects of treatment for as long as possible. Treatment is still available when you need it, but this might not be for months or years. You might never need treatment.

Treatment is just as effective if it is saved until it is needed.

“Once the shock of a cancer diagnosis has sunk in, you expect the next stage to be treatment. When it’s suggested we will ‘watch and wait’, lots of thoughts flood your imagination. But I’ve now avoided chemotherapy for more than 10 years.

Jackie, diagnosed with splenic marginal zone lymphoma in 2008, age 53

We produce a separate book on active monitoring for lymphoma. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a free copy.
You might have active monitoring when you are first diagnosed with lymphoma, or after a course of treatment that has shrunk your lymphoma but has not got rid of it completely.

Your medical team might suggest active monitoring if:

- your lymphoma is not causing troublesome symptoms
- your lymphoma is not growing quickly
- your blood tests don’t show any significant problems
- your lymphoma is not affecting any of your major organs (such as your heart, lungs or kidneys).

**Being on active monitoring**

When you are on active monitoring, you have regular check-ups with your doctor, clinical nurse specialist or another member of your medical team to make sure your lymphoma doesn’t need treatment. They talk to you about how you’re feeling and whether you’ve noticed any change in your symptoms or any new symptoms. They might also examine you and take blood tests. If necessary, you might have a scan but this isn’t routinely done unless you have new symptoms.

If you notice a change in symptoms, feel unwell or have concerns about your health, contact your medical team straightaway. Don’t wait for your next appointment.
Starting treatment


You might end active monitoring and start treatment if:

• your symptoms become difficult to cope with
• you develop B symptoms
• your lymphoma starts to grow quickly
• your test results suggest that your lymphoma is affecting your organs or your bone marrow.

Some people need treatment soon after they are diagnosed. Others don’t need treatment for many years. Some people never need treatment.

Questions to ask about active monitoring

• Why don’t I need treatment straightaway?
• Are there any risks in delaying treatment?
• How long might I be on active monitoring?
• How will you know when I need treatment?
• Is there anything I should look out for?
• Who should I contact if I have any concerns?
• Can I work and carry on with normal activities?
• What support is available?
Chemotherapy

Chemotherapy is treatment that uses drugs to kill cancer cells. Most chemotherapy drugs work by killing cells that are dividing to make new cells. Some chemotherapy drugs work on cells that are not dividing.

Visit lymphoma-action.org.uk/Chemotherapy to watch an animation explaining how chemotherapy works.

Cancer cells, including lymphoma cells, are very sensitive to the effects of chemotherapy. Some healthy cells, such as blood cells, hair follicles or skin cells, also divide rapidly and can be affected by chemotherapy. This is responsible for some of the side effects of chemotherapy (pages 87-103).

Chemotherapy usually involves treatment with a number of different drugs (known as a chemotherapy regimen) that work in different ways to kill as many cancer cells as possible.

I found having chemotherapy wasn’t as difficult as I thought. Medications to alleviate symptoms were good and I received great care from my hospital team.
Julia, diagnosed with follicular lymphoma in 2018
Having chemotherapy

Most people have chemotherapy for low-grade non-Hodgkin lymphoma as an outpatient in a day care unit or chemotherapy unit. You go to the hospital on treatment days and go home afterwards. You usually have blood tests beforehand or as soon as you arrive to make sure you are well enough for your treatment.

You might need to stay in hospital if you are having more intensive chemotherapy, or if you develop side effects such as an infection or very low blood counts (page 90).

In between your treatment days, you usually have medicines to take at home. Some of these might be part of your chemotherapy and some of them might be to help control any side effects you develop (pages 87-103).

You will be given a 24-hour telephone number to call for advice if you feel unwell when you are at home.

You have chemotherapy in cycles – a round of treatment followed by a rest period to give your body time to recover. During each cycle, you might have chemotherapy on several days or just one, depending on the exact treatment regimen you need.

The number of cycles you have and how often you have treatment depends on the chemotherapy regimen. A whole course of chemotherapy usually takes several months.
Having intravenous chemotherapy

Most chemotherapy is given intravenously (as a drip or injection into a vein). You might have it through:

- A ‘cannula’ – a small, soft plastic tube that usually goes into a vein in the back of your hand. You have a new one put in each time you go for treatment. This is the most common way to have treatment for low-grade non-Hodgkin lymphoma.
- A ‘central venous catheter’, ‘central line’ or ‘PICC line’ – a longer plastic tube that goes into a vein in your arm or under the skin of your chest and ends in a larger vein near your heart. Examples include a Hickman® line and a Groshong® line. A central line usually stays in for all of your treatment. You might have one fitted if you need an intensive chemotherapy regimen. You go to a day ward to have your line cleaned regularly, or a nurse might show you how to look after it at home.
- A ‘port-a-cath’ – a type of central line that ends in a port or chamber just under the skin on your chest. Your treatment can be injected into the port using a special needle.
Figure: A Hickman® central line

Figure: A PICC line
Your nurse can inject some chemotherapy drugs straight into your cannula or central line over a minute or two. Other chemotherapy 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 are having.

Figure: Having treatment through a drip

Tell your nurse if you have any discomfort during your chemotherapy. They can check the drugs are going in properly.
Having oral chemotherapy

You might have some chemotherapy drugs as tablets or capsules that you take by mouth (orally). Your medical team should give you instructions on what to take and when, and how to store the drugs.

It is important that chemotherapy tablets are not handled by anyone other the person who is taking them to avoid damaging healthy cells. If you are helping someone take chemotherapy, wear gloves when handling any tablets or capsules.

Use a tablet organiser to make sure you take all your medicines at the right time on the right days of each treatment cycle.

It was decided I should receive a 6-month course of chlorambucil, a type of chemotherapy given in tablet form. This entailed very regular visits to the oncology clinic to check blood results.

Christine, diagnosed with follicular lymphoma in 2000
Chemotherapy regimens for low-grade non-Hodgkin lymphoma

Most chemotherapy regimens are known by a series of letters, usually the initials of the drugs included.

We outline some of the more common regimens here but your medical team might recommend a different option. They should tell you about your treatment, including what you have and when. They should also tell you what side effects you might experience.

Ask your team if there is anything about your treatment that you don’t understand.

Tell your medical team if you feel unwell or have any side effects during your treatment. There are things they can do to help.

For information about the side effects of lymphoma treatment and tips on how to cope with them, see pages 87 to 103.
Common regimens for low-grade non-Hodgkin lymphoma

The regimens listed in this section are usually combined with *antibody therapy* (page 71), either:

- rituximab – in which case an ‘R’ is added to the name of your chemotherapy regimen
- obinutuzumab – in which case an ‘O’ is added to the name of the regimen, (or sometimes a ‘G’, after its trade name: Gazyvaro).

The most common chemotherapy regimens for low-grade non-Hodgkin lymphoma are:

- bendamustine
- CVP: *cyclophosphamide*, *vincristine* and *prednisolone*
- CHOP: *cyclophosphamide*, doxorubicin (or *hydroxydaunorubicin*), vincristine (also known as *Oncovin*) and *prednisolone*.

Bendamustine is usually given every 28 days. A single *cycle* of CVP or CHOP is usually 21 days. You have all the drugs except prednisolone (a *steroid*) as a drip or injection into a vein on day 1 of each cycle. You take prednisolone by mouth every day for the first 5 days of each cycle. Then you have a break before the next cycle. The number of cycles you have depends on how much lymphoma you have in your body and how you respond to treatment.
Other chemotherapy regimens

Some types of low-grade non-Hodgkin lymphoma are treated with other chemotherapy regimens, including:

- chlorambucil, on its own or with antibody therapy
- DRC: dexamethasone, rituximab and cyclophosphamide.

If you have mantle cell lymphoma (page 146) and you are fit enough, your chemotherapy is likely to include a drug called cytarabine. You might have this in between cycles of a standard chemotherapy regimen, or in a more intensive regimen, such as:

- DHAP: dexamethasone, high-dose cytarabine (also known as Ara-C) and cisplatin (or platinum)
- the ‘Nordic protocol’: rituximab plus alternating cycles of maximum dose CHOP (maxi-CHOP) and high-dose cytarabine.

These are usually followed by a stem cell transplant.

There are many other regimens available. Your medical team might offer you a regimen that is not listed here but that they consider to be the best choice for your type of lymphoma and your other health considerations.

Search ‘chemotherapy drugs’ at macmillan.org.uk to find out more about particular chemotherapy drugs or regimens.
Questions to ask about your chemotherapy regimen

- What chemotherapy regimen do you recommend for me?
- How often will I have treatment?
- How long does each treatment session take?
- How many cycles will I have?
- What side effects or late effects might I experience?
Antibody therapy

Antibodies are naturally made by your immune system. They recognise and stick to particular proteins on the surface of cells that don’t belong in your body, such as viruses or bacteria. Once they have stuck to these proteins, they either kill the foreign cell directly or help your immune system to find it and destroy it.

**Antibody therapy** uses antibodies that have been specially made in a lab to target a protein on a cancer cell. It is sometimes known as ‘immunotherapy’ because it works through your immune system.

*Figure: Antibodies stick to specific proteins on a cell*
Having antibody therapy

At the time of writing, two antibody therapies are available to treat low-grade non-Hodgkin lymphoma in the UK: rituximab and obinutuzumab. They stick to a protein called CD20 on the surface of B cells.

Most people have antibody therapy combined with chemotherapy (‘chemo-immunotherapy’). Some people have rituximab on its own.

- If you are having rituximab with chemotherapy, you have it on the first day of each treatment cycle.
- If you are having rituximab on its own, you usually have it once a week for 4 weeks.
- If you are having obinutuzumab with chemotherapy, you have it on day 1, day 8 and day 15 of your first treatment cycle. After this, you have it on the first day of each treatment cycle.

Before you have antibody therapy, you have medicines such as antihistamines and steroids to help prevent any reactions to it. You then have the antibody therapy through a drip into a vein (page 65). You have your first dose slowly. It might take a few hours. You have the rest of your doses more quickly unless you have serious side effects the first time. If you are having rituximab, you might have it as an injection under your skin (subcutaneously) after the first dose.
The most common reactions to antibody therapy are shivers, fevers and flu-like symptoms. This is called an ‘infusion reaction’. It is more likely to happen with your first dose, which is why you have it more slowly.

Some people have an allergic reaction to antibody therapy. If this happens, you are monitored in hospital for a while. You might need to have antibody therapy more slowly in the future, or stop the treatment altogether.

**Targeted therapy**

**Targeted therapies** aim to affect lymphoma cells more precisely than chemotherapy or radiotherapy, reducing the effect of treatment on healthy cells. They act on particular proteins or pathways that are more important in lymphoma cells than in healthy cells. Clinical trials are researching lots of different targeted therapies, some of which are, or might soon be, available to treat lymphoma.

At the time of writing, only one targeted therapy is licensed for initial treatment of low-grade non-Hodgkin lymphoma. It is called bortezomib.

Other targeted therapies are available to treat some types of low-grade non-Hodgkin lymphoma that have come back or not responded to initial treatment. These are covered on pages 117 to 118.
Having bortezomib

Bortezomib stops proteins inside cells from being broken down. This seems to be particularly harmful to certain types of lymphoma cells, causing them to stop working properly and die.

You might have bortezomib if you have mantle cell lymphoma (page 146) that has not been treated before and you’re not able to have a stem cell transplant.

You usually have bortezomib combined with rituximab, cyclophosphamide, doxorubicin and prednisone (known as R-CHP). You have it as an injection into a vein (intravenously) or just under your skin (subcutaneously) twice a week for 2 weeks followed by a 10 day rest period. You have six to eight cycles of treatment.
Radiotherapy uses high-energy X-rays and other types of radiation to kill cancer cells. The high-energy radiation is directed to precise areas of your body so it is usually used to treat lymphoma that is only in one or two places rather than spread throughout your body.

Radiotherapy kills cells by stopping them from dividing. Lymphoma cells are very sensitive to radiotherapy, but it can affect healthy cells as well as cancer cells.

Radiotherapy might be used to treat early stage low-grade non-Hodgkin lymphoma that is only affecting one part of your body. In some cases, this can cure the lymphoma. Radiotherapy might also be used to treat advanced stage lymphoma if there are particular areas of lymphoma that are causing problems.

**Figure: Radiotherapy**
Having radiotherapy

If you need radiotherapy, you are treated by a clinical oncologist (a doctor who specialises in treating cancer with radiotherapy; also known as a radiation oncologist). Radiotherapy is only available at specialist centres, so you might need to travel for your treatment.

You go to the radiotherapy department to plan your treatment. You might need several visits, including some tests and scans.

Your clinical oncologist plans the total dose of radiotherapy you need and how many treatment sessions it should be spread over.

When you have radiotherapy, it is very important that precisely the same area is treated each time. You might have up to three tiny dots tattooed onto your skin to make sure the X-ray beams target exactly the right place. If you are having radiotherapy to your head or neck, you might need to wear a special mask to make sure you’re in the right position.
You have radiotherapy every day during the week with a rest at weekends. You can usually go home after each treatment. Most people have treatment for 1 to 3 weeks.

Each radiotherapy session takes around 15 minutes. Most of this time is to make sure you are in the correct position. The treatment itself only takes a few minutes. It doesn’t hurt. During the treatment, the radiotherapy staff leave the room but they can see you and hear you all the time.

Tell a member of staff if you are worried about anything.

Radiotherapy for lymphoma does not make you radioactive. There is no risk to people close to you.

-Having radiotherapy was very straightforward. The overriding requirement is not to move. I found that the best way to cope was to think about totally different things. -Julian, diagnosed with nodal marginal zone lymphoma, age 66

For information about the side effects of lymphoma treatment, see pages 87 to 103, which include tips on how to cope with the side effects.
Stem cell transplant

Some treatments for lymphoma involve having high-dose chemotherapy. High-dose chemotherapy can reduce the risk of your lymphoma coming back (relapsing). However, it can permanently damage your stem cells (special cells in your bone marrow that make all your red and white blood cells). This stops you making the blood cells your body needs.

A stem cell transplant is a procedure that replaces damaged or destroyed stem cells with healthy stem cells.

Usually, the healthy stem cells are collected from your own bloodstream before your high-dose chemotherapy and are given back to you afterwards. This is known as an autologous (self) stem cell transplant. Occasionally, the stem cells come from a donor. This is called an allogeneic stem cell transplant.

Your medical team might recommend a stem cell transplant after your initial treatment if you have a type of lymphoma that has a high risk of relapsing (for example, fast-growing mantle cell lymphoma; see page 146). They might also recommend a stem cell transplant if you have another type of low-grade non-Hodgkin lymphoma that has come back or not responded to initial treatment.
Having a stem cell transplant

If you need a stem cell transplant, healthy stem cells are collected either from your own blood (for an autologous transplant) or from a donor (for an allogeneic transplant).

You then have high-dose chemotherapy every day, typically for 6 days. After this you have the stem cells through a drip, a bit like a blood transfusion. The stem cells settle in your bone marrow where they start to make new blood cells. While they are settling into your body, you have a very high risk of infection.

Stem cell transplants are very intensive, especially allogeneic transplants. You need tests beforehand to make sure you are fit enough to have one. You usually stay in hospital for several weeks to have a transplant. After you go home, it can take several months to recover.

If your medical team thinks a stem cell transplant is suitable for you, they will talk to you in detail about it. You might be treated by your usual medical team or be referred to a haematologist who specialises in transplants.
1. **Preparation**
You have tests and scans to make sure you are fit enough to have a stem cell transplant, and treatment to get your body ready.

2. **Stem cell collection**
Your stem cells are collected from your bloodstream and frozen until they are needed.

3. **Conditioning**
You have high-dose anti-cancer therapy to treat your lymphoma. This destroys your remaining stem cells.

4. **Stem cell infusion**
Your stored stem cells are thawed and given back to you.

5. **Engraftment**
Your infused stem cells settle into your bone marrow and start making new blood cells.

**Figure: Autologous stem cell transplant process**

We have separate information on stem cell transplants, including a book on autologous (self) stem cell transplants. Visit lymphoma-action.org.uk/SCT or phone 0808 808 5555 to learn more.
**Maintenance therapy**

**Maintenance therapy** is treatment that is sometimes given after an initial course of treatment has put lymphoma into remission (the lymphoma has shrunk or disappeared completely). It aims to make your remission last as long as possible by ‘mopping up’ any lymphoma cells that might be left in your body.

You might be offered maintenance therapy if you have follicular lymphoma (page 145) or mantle cell lymphoma (page 146) that has responded well to a course of treatment.

Maintenance therapy usually involves having an injection of an antibody therapy (page 71) once every 2 to 3 months. If your lymphoma stays under control, you usually carry on having it for 2 or 3 years.

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*I was put on maintenance rituximab and have needed no other treatment since then. I have check-ups every 4 months and feel I am doing wonderfully well. But I am realistic and know it may come back.*

Pat, diagnosed with follicular lymphoma, age 56
Treatments for symptoms and side effects

You have some medicines that don’t directly treat your lymphoma but are still an important part of your care. These ‘supportive medicines’ are used to prevent or treat symptoms or side effects and help you feel better in yourself.

Medicines to help with side effects

You have medicines to help prevent side effects developing, and to treat them if they do develop. This might include anti-sickness drugs (sometimes called ‘antiemetics’), pain relieving medicines, antacids or antibiotics.

Steroids

Steroids are drugs that mimic hormones produced naturally by your body. They are routinely used alongside chemotherapy to treat some types of lymphoma, to help control nausea (feeling sick) and, if needed, to treat allergic reactions to other medicines.

You usually have steroids, such as prednisolone or dexamethasone, as tablets. Side effects of steroids can include difficulty sleeping, mood changes, raised blood sugar, and increased appetite. These side effects are more likely if you take high doses of steroids or take them for a long time. Side effects should go away after treatment.
Blood transfusions

If your red blood cell count is low (anaemia), you might need a blood transfusion. If your platelet count is low (thrombocytopenia), you might need a platelet transfusion.

I did carry on doing a bit of gardening, but I had to avoid cuts and scratches as my haemoglobin and platelet counts were low. For that reason, I had several transfusions of blood or platelets.

Peter, diagnosed with mantle cell lymphoma in 2019

Growth factors

Growth factors are hormones that occur naturally in your body. They encourage your bone marrow to make blood cells. Man-made growth factors are sometimes used to boost your blood cell counts (page 90) if they drop too much during chemotherapy.

The growth factor most commonly used is called ‘granulocyte-colony stimulating factor’ (G-CSF). You have G-CSF as an injection into the fatty tissue under your skin (a subcutaneous injection), usually into your tummy, the top of your leg or the top of your arm. You (or a friend or family member) might be taught how to give yourself the injections at home. Alternatively, a community nurse might visit you to give you your injections. You must keep G-CSF in the fridge.
The injections can sting and you might have side effects such as flu-like symptoms, fevers, bone pain or headaches. Mild painkillers such as paracetamol can help, but ask your medical team before you take anything. If you feel unwell during your treatment, contact your hospital straightaway.

**Plasmapheresis**

If you have Waldenström’s macroglobulinaemia (page 153), you might have high levels of abnormal antibodies in your blood. This can make your blood too thick. If this happens, you might need to have it thinned by a procedure called ‘plasmapheresis’ (plasma exchange).

*Search ‘therapeutic apheresis treatments’ at nhsbt.nhs.uk for a downloadable factsheet on plasma exchange.*
Summary

• If you have low-grade lymphoma that isn’t causing many problems, you might have active monitoring before you start treatment.

• Chemotherapy is treatment that uses drugs to kill cancer cells. You usually have chemotherapy as an outpatient and go home afterwards. Most chemotherapy is given intravenously every few weeks.

• Most people have antibody therapy combined with their chemotherapy (chemo-immunotherapy). It is given by injection.

• Radiotherapy uses high-energy X-rays to kill cancer cells. You usually have radiotherapy as an outpatient and go home afterwards. You have radiotherapy every day during the week with a rest at weekends.

• A stem cell transplant is an intensive form of treatment that involves high-dose chemotherapy followed by treatment to help your bone marrow recover.

• Some people have maintenance therapy to reduce the risk of relapse. It usually involves having an injection of rituximab every 2 months.

• You have medicines to treat or prevent side effects or symptoms. These might include steroids, growth factors, anti-sickness drugs, antacids and antibiotics.
I am pleased that I did not know anything about the side effects of my chemotherapy. I was aware that I might feel sick but, surprisingly, I never did. As the weeks progressed though, my ‘dip’ days became harder alongside the fatigue, the aching in my bones, the loss of appetite and most of all the mouth blisters. I can reflect now about how hard it was, particularly the last two cycles. Having wonderful support was key to keeping me going.

Debbie, diagnosed with follicular lymphoma in 2011
Coping with treatment

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Coping with common side effects of treatment

It is hard to predict exactly how you will feel during your treatment. Some people are able to carry on almost as usual. Other people need to make changes, at least for a while.

Keeping as physically healthy as possible can help your body cope better with lymphoma treatment. It can also help reduce some of the side effects of treatment, and improve your quality of life.

If you can, get some exercise every day, even if it’s just a short walk. Try to eat a healthy diet that includes plenty of fruit and vegetables.

Questions to ask about side effects

• What side effects might I get? How long might these last?
• Are there any potential late effects (side effects that happen months or years after treatment finishes – see pages 87-103)?
• Will I be able to carry on my normal day-to-day routine during treatment?
The side effects you might develop depend on what treatment you are having. Your medical team should give you information about your treatment and what to expect, but it is impossible to say what side effects you will get. Each person gets slightly different side effects, even if two people are having the same treatment.

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

Most side effects are short-term. Some develop soon after you start treatment but some might not develop until later. Sometimes treatment can have longer-term or late effects (page 129). Your medical team should discuss this with you before you start treatment.

Tell your medical team about any side effects you have or if you feel unwell during your treatment. There are often things they can do to help.
Low blood counts and risk of infection

Chemotherapy, radiotherapy and targeted therapies can cause temporary damage to your bone marrow. Your bone marrow makes your body’s blood cells. These include:

- **White blood cells**, which help to fight infection. Neutrophils are the most important type of white blood cell.
- **Red blood cells**, which carry oxygen around your body.
- **Platelets**, which help your blood to clot. This reduces bleeding and bruising.

You have regular blood tests to check your blood counts.

Low neutrophil count

A low neutrophil count (neutropenia) is common after many types of chemotherapy and some targeted therapies. It can also develop after radiotherapy targeted at large areas. Depending on the exact treatment you’re having, your neutrophil count is usually lowest about 7 to 12 days after chemotherapy, although it could stay low for longer.
Having a low neutrophil 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 antibiotics and careful monitoring.

Call the 24-hour contact number you’ve been given if you develop any signs of infection.

To reduce your risk of developing an infection, you might have antibiotics and antiviral medicines to take at home, even if you don’t have an infection. This is called ‘anti-infection prophylaxis’.

Your medical team checks your neutrophil count before each cycle of treatment. If your neutrophil count is too low, your next cycle of treatment might be delayed until you have enough neutrophils. This could just be a day or two later than planned but it could be longer. You might have drugs such as growth factors (page 83) to help boost your neutrophil count.

For one week in each cycle, my immunity was low and I had to keep away from the public and avoid visits from known bug-carriers. I also had to stop teaching, as schools are hotbeds for bugs.

Peter, diagnosed with mantle cell lymphoma in 2019
Contact your medical team if you have any of the following, no matter how minor they might seem:

- fever (temperature above 38°C)
- hypothermia (temperature below 35°C)
- shivering
- chills and sweating
- feeling generally unwell, confused or disorientated
- earache, cough, sore throat or sore mouth
- blocked nose
- shortness of breath
- redness and swelling around skin sores, or injuries to intravenous lines
- diarrhoea or vomiting
- a burning or stinging sensation when weeing, or weeing more often than usual
- unusual genital discharge or itching
- unusual stiffness of the neck and discomfort around bright lights
- any new pain.
Tips to lower your infection risk

- Have a bath or shower regularly.
- Wash your hands before meals, after using the toilet, and after using public facilities.
- Avoid places where you have a higher risk of catching an infection, such as swimming pools, public transport at peak time, or crowded shops. Consider wearing a face covering if you can’t avoid crowded places.
- Avoid contact with people who are unwell.
- Don’t eat anything that is past its use-by-date.
- Use refrigerated food within 24 hours of opening.
- Do not reheat takeaway meals.
- Take care when handling pets – avoid bites or scratches and wash your hands after any contact with an animal. If possible, get someone else to deal with animal waste.
- Wear gloves for gardening.
- Visit your dentist before you start lymphoma treatment – you might not be able to have any dental work done during or soon after treatment because of the risk of infection.

Your medical team might advise you to cut out certain foods that might cause infections, such as ‘bio’ yoghurt or undercooked eggs, meat or fish. These foods can contain live bacteria.

For more information about infection and food safety, visit lymphoma-action.org.uk/Infection
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 a blood transfusion.

Tell your doctor if you feel short of breath, unusually tired, dizzy or have new aches and pains.

Low platelet count

A low platelet count is called thrombocytopenia. If you have thrombocytopenia, you might bruise easily or bleed more or for longer than usual after minor injuries. You might have nose bleeds or bleeding gums. You might develop a rash of tiny red spots on your skin or mouth, or notice blood in your wee or poo.

Tell your medical team if you notice any signs of bleeding or bruising or if you feel faint or clammy.

If your platelet count is very low, your medical team might adjust your treatment. You might need a platelet transfusion.

If you have a low platelet count, take extra care when using tools or sharp objects, for example when cooking or gardening. Avoid contact sports.
Feeling sick or being sick

Some people who have chemotherapy or radiotherapy experience nausea (feeling sick) or vomiting (being sick). Sickness can usually be controlled by anti-sickness drugs (antiemetics). There are lots of different anti-sickness drugs available and you might have to try a few to find what works best for you.

Tell your medical team if you feel sick, even if you have already had treatment for it.

Tips to help with sickness

• Take your anti-sickness drugs regularly as prescribed. Don’t wait until you feel sick.
• Eat several small meals throughout the day when you feel like it. Eat food that appeals to you.
• Avoid foods that have a strong smell.
• Try foods and drinks containing ginger, such as ginger biscuits and ginger tea.
• Try relaxation techniques such as breathing exercises, meditation or mindfulness.
• Try travel sickness wristbands, which you can buy from pharmacies.
• Keep your surroundings as peaceful and clean as possible.
• Get some fresh air regularly.
Sore mouth

Many lymphoma treatments damage the cells lining your mouth. This can be very painful. It can cause mouth ulcers, pain when you swallow or a dry, sore mouth and lips (oral mucositis). You might also develop a yeast infection in your mouth (oral thrush), which causes small, white patches.

Tell your medical team if you have a sore mouth. They might prescribe painkillers, a special mouthwash, artificial saliva or other treatments to help. If you have oral thrush, you might have tablets, or gel or liquid medicine that you apply directly to your mouth.

A sore mouth usually gets better as you recover from each cycle of lymphoma treatment.

Tips to help a sore mouth

• Keep your mouth clean and rinse after meals.
• Use an alcohol-free mouthwash to soothe discomfort and prevent infection. You can dilute it if it causes stinging.
• Use a soft-bristled toothbrush.
• Keep your lips moist with lip creams or balms.
• Sip drinks through a straw. Try sucking an ice lolly or ice cubes.
• Avoid smoking and drinking alcohol.
• Avoid rough, dry or spicy foods.
• Try cool foods that are easy to swallow.
Difficulty eating

Some lymphoma treatments can reduce your appetite or make you feel full very quickly. You might get indigestion or heartburn. Food might taste different or you might be sensitive to particular smells and tastes. If you have a dry mouth, you might find it hard to swallow.

Tell your medical team if you are struggling to eat. They might refer you to a dietitian. Talk to your medical team before trying any nutritional supplements.

Tips to help with eating

- Eat little and often or whenever you are hungry, whether it is your usual mealtime or not.
- Try foods with a stronger taste, such as savoury foods flavoured with herbs, spices and chutneys.
- Choose high-energy snacks and full-fat foods.
- When you can, eat with others in a pleasant environment.
- Take gentle exercise to stimulate your appetite.

Once you finish treatment, changes to your taste and appetite should settle down, so try to re-introduce any foods that you stopped enjoying.
Bowel problems

Lymphoma treatments, anti-sickness medicines and painkillers can cause diarrhoea, constipation or wind. Bowel problems are usually mild and get better when your treatment finishes.

Tell your medical team if you have any bowel problems that aren’t normal for you. They might be able to give you medicine to help. They might ask you for a stool (poo) sample to make sure you don’t have an infection.

Tips to help bowel problems

- If you are constipated, drink plenty of fluids and eat a high-fibre diet containing wholegrain cereals and wheat, lentils, pulses, fruit and vegetables. You might find it helps to have a hot drink in the morning or to take gentle exercise, such as walking.
- If you have diarrhoea, it’s important you drink plenty of fluids to keep yourself hydrated. Try to eat low-fibre foods such as peeled cooked potatoes, white rice, white bread or dry crackers.
- Eating and drinking slowly or drinking peppermint tea might help reduce wind. Avoid fizzy drinks.

Tiny changes such as drinking or exercising less can cause constipation. But after cancer treatment, it’s something I’ve had to learn to live with.
Debbie, diagnosed with follicular lymphoma in 2011
Sore skin

If you have radiotherapy, the skin in the treated area might become dry, sore or itchy. This usually gets better in a few weeks. You might also notice changes in your finger or toe nails, which can be caused by radiotherapy or chemotherapy. Your nails might change colour, or become dry and brittle. They might come off completely. They grow back gradually after your treatment ends.

Some lymphoma treatments can make your skin sensitive to sunlight.

Tips to help sore skin

• Avoid using soap, talcum powder or deodorant on sore areas. Try using hypoallergenic products.
• If you are having radiotherapy, use the moisturising treatment (emollient) that your medical team recommends.
• Avoid rubbing your skin. When washing, use lukewarm water and pat yourself dry with a towel.
• Use an electric razor rather than wet shaving, or avoid shaving altogether.
• If your skin is itchy, wear loose-fitting, lightweight clothes made from soft cotton, silk or bamboo.
• Protect your skin from the sun: avoid the sun when it’s at its strongest, wear a sun hat and use high-factor sunscreen (at least SPF 30).
Hair loss

Some chemotherapy drugs used to treat low-grade non-Hodgkin lymphoma cause hair loss. Radiotherapy also causes hair loss, but only in the area treated.

Your hair usually begins to fall out within a couple of weeks of starting treatment. You should notice it start to grow back within 2 to 3 months of finishing your treatment but it can take longer.

Many people find losing their hair difficult. It can be helpful to prepare by having your hair (including any facial hair) cut short beforehand. When your treatment starts, wearing a hairnet or towelling turban to bed helps to collect any hair that falls out at night time.

- If you choose to cover your hair loss, there are lots of options, such as wigs, scarves, hats and bandanas. Find a look you feel comfortable with.
- Be gentle with your hair and scalp. Use a soft hairbrush. Avoid chemical products. If your scalp is dry, try massaging a mild moisturiser into it.

Talk to your medical team if you are concerned about losing your hair.

Macmillan Cancer Support have information about wigs, hats, scalp care and more. Visit macmillan.org.uk and search ‘Hair loss’.
Fatigue

Fatigue is extreme tiredness that isn’t related to physical activity and doesn’t necessarily go away after resting. It can happen because of the lymphoma itself or the treatment you are having.

Fatigue affects people differently. Some people find they can’t do as much as they used to. Others feel so tired they can’t do their usual daily activities.

Fatigue usually gets better gradually but it can last for months after your treatment has ended. For some people, it can last a year or more, although it usually gets less troublesome over time.

Tips to help with fatigue

• Follow the ‘three Ps’: plan, pace and prioritise.
• Take regular light exercise, such as walking.
• Take short rests throughout the day and try to get into a regular sleeping pattern at night.
• Accept help with day-to-day tasks.
• Make time to see friends and take part in normal social activities.
• Eat a healthy diet.
Nerve damage (peripheral neuropathy)

Some lymphoma treatments can damage your nerves, most often in your hands and feet. This is called peripheral neuropathy. It usually causes numbness or changes in sensation, tingling and sometimes pain in your fingers and toes. It can affect other places, too. It can cause weakness, such as poor grip or difficulty opening jars.

Neuropathy usually develops after several cycles of treatment. For most people, symptoms get better after finishing treatment, but it can take weeks or months. For some people, it never goes away completely.

Tell your medical team straightaway if you have symptoms of peripheral neuropathy. They might adjust your treatment to stop your symptoms getting worse, or prescribe painkillers that are effective against peripheral neuropathy.

You must notify the Driver and Vehicle Licensing Agency (DVLA) if you have peripheral neuropathy.

Tips to help with peripheral neuropathy

- Take care to avoid injuring your fingers and toes.
- Keep your hands and feet warm.
- Gently massage or bend and stretch your fingers and toes for a few minutes, four times a day.
- Wear supportive shoes and avoid high heels.
‘Chemo brain’ (cancer-related cognitive impairment)

Some people have trouble remembering things or concentrating properly when they have lymphoma. This is probably due to the effects of both the lymphoma itself and the lymphoma treatment.

Although this is often called ‘chemo brain’, it doesn’t only affect people being treated with chemotherapy. Some people describe it as a ‘mental fog’ or feeling slightly detached from the world around them. Its medical name is cancer-related cognitive impairment.

The effects of chemo brain usually get better gradually after finishing treatment, although it often takes many months and occasionally years.

If you are affected by chemo brain, tell your medical team.

Tips to help with chemo brain

• Focus on one thing at a time.
• Write things down: use a diary, app or notebook.
• Plan your day so that you do difficult things when you feel at your best.
• Ask for help where you can.
• Try to keep your mind active by playing games, reading or solving problems.
Coping with day-to-day life

It is hard to predict how your treatment will affect your everyday life. You might need to adjust to changes in your physical or emotional health.

Work and finances

Some people carry on working during treatment for lymphoma. Others need to take time off.

Your employer must, by law, make any ‘reasonable adjustments’ you need during and after your treatment. This might involve reducing or changing your working hours, altering the work you do, or taking time off for appointments. Talk to your employer and your medical team about the support you might need.

If you are self-employed, think about how you will manage your work and finances. You might qualify for financial support from the government. Your key worker might be able to help you access this.

If you’re already receiving financial support from the government, let them know you have lymphoma.

Macmillan Cancer Support produce detailed information about work and cancer. Visit macmillan.org.uk/Work
**Studying**

If you’re at school, college or university, you’re likely to need time off from your studies, particularly during treatment. Let your school, college or university know what is happening so that they can support you.

You might want to take a short break from studying and do work when you can. You might prefer to take a longer time out and return to studying the next academic year when you have fully recovered.

**Hobbies and socialising**

While you’re being treated for lymphoma, allow yourself time to do the things you enjoy. When you feel well enough, seeing friends, getting out or doing a hobby can make you feel more like yourself and improve your emotional and physical wellbeing. Try to stay as physically active as possible, to keep your body as healthy as you can. Regular exercise can also reduce the impact of side effects.

Remember that there might be times when you should avoid crowds and public places because of the risk of infection. Your hospital team should give you advice about this.
Holidays and special events

Talk to your medical team before planning any holidays or special events. They can advise you based on your individual situation.

It might be advisable to stay close to home during certain times of your treatment and recovery.

If you are thinking about going on holiday once you have finished treatment, talk to your medical team. You might need to consider where you travel to, your accommodation, whether you need any vaccinations and what travel insurance you need.

“I get on with life as normal. But, having follicular lymphoma, I do think about whether it will return, but then I jog myself back into the here and now and enjoy each day as it comes.”
Malcolm, diagnosed with follicular lymphoma, age 60
Sex and contraception

You might not feel like having sex when you are going through treatment or for some time afterwards. Be open with your partner and let them know how you feel. There is no reason you shouldn’t have sex during treatment if you feel like it, but be aware that you need to take extra precautions.

Use contraceptives throughout your treatment if there is any chance that you or your partner could become pregnant. Some treatments can damage sperm or eggs and could be harmful to a developing baby. If you do become pregnant, it can make it more difficult to treat your lymphoma.

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

People who have had lymphoma are usually advised to wait for 1 to 2 years after finishing treatment before trying to start a family. There is more information on lymphoma treatment and fertility on page 131.

Everybody’s circumstances are different, so it is important to discuss these issues with your medical team.
Summary

• No one can tell you exactly how treatment for low-grade non-Hodgkin lymphoma will affect your day-to-day life.
• You might need to make changes to your work or studies, personal life, or holiday plans.
• You are likely to experience side effects but it’s difficult to predict what side effects you’ll get and how they will affect you. Your medical team should tell you the most common side effects of your treatment.
• There are lots of things you can do to help you cope with side effects.
• Talk to your medical team about the support available to you.
A diagnosis isn’t necessarily as bad as it may seem at first. I feel very lucky that each time it has relapsed new treatments were offered and that many years later I am able to tell my story.

Carole, diagnosed with follicular lymphoma in 1984
What happens if low-grade non-Hodgkin lymphoma comes back or doesn’t respond to treatment?

What is relapsed or refractory lymphoma? 112
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Coping with the fear of relapse 114
How is relapsed or refractory low-grade non-Hodgkin lymphoma treated? 115
What happens if lymphoma relapses again? 120
What is relapsed or refractory lymphoma?

Low-grade lymphoma usually responds well to treatment. However, at some point, it is likely to come back. This is known as ‘relapsed’ lymphoma. It might not happen for many years.

Occasionally, lymphoma doesn’t respond well to the first choice of treatment. This is called ‘refractory’ lymphoma. It is usually treated in a similar way to relapsed lymphoma.

Having relapsed or refractory lymphoma can be very distressing, but many people are successfully treated again.

As treatment options for low-grade non-Hodgkin lymphoma improve, remissions are lasting longer. Relapse might not happen for many years. You might have long periods when you feel well, and other times when you need treatment.
What happens if lymphoma relapses?

If your lymphoma relapses, you are likely to be the first person to notice. It might come back where it was before or it might affect a different part of your body. You might have the same symptoms as before or different symptoms.

If you’re worried that your lymphoma has relapsed, contact your medical team straightaway.

If your medical team thinks your lymphoma might have relapsed, you have tests and scans to confirm it and help your team decide on the most appropriate treatment for you.

Transformation

Occasionally, low-grade lymphoma changes (transforms) into a faster-growing type of lymphoma.

If your medical team thinks your lymphoma might have transformed, you are likely to have a biopsy to check for faster-growing cells. Transformed low-grade lymphoma is usually treated like high-grade lymphoma.

We have a separate book on high-grade non-Hodgkin lymphoma. Visit lymphoma-action.org.uk/Books or phone 0808 808 5555 to order a copy free of charge.
Coping with the fear of relapse

It is natural to feel anxious about the possibility of your lymphoma relapsing. Whenever you feel ill, you might worry it’s the lymphoma again. It can be difficult to get the right balance between monitoring your health and worrying unnecessarily over minor symptoms.

Everyone copes with the fear of relapse in their own way. It can help to talk about your concerns with your medical team, your family and friends, or with other people affected by lymphoma.

Tips for coping with the fear of relapse

• Ask your medical team what signs of relapse to look out for.
• Talk to family, friends or other people affected by lymphoma.
• Consider talking through your fears with a professional, for example a counsellor.
• Try to stay active and do things you enjoy.

Our Helpline Services (page 159) offer emotional support if you’d like talk about your concerns. They can also put you in touch with our buddy service.
How is relapsed or refractory low-grade non-Hodgkin lymphoma treated?

If your lymphoma doesn’t respond to treatment or comes back after treatment, it can be very upsetting. However, there are several treatment options that can be successful. The treatment you have depends on:

- how the lymphoma is affecting you
- the type of treatment you’ve already had and how your lymphoma responded to it
- the treatment options that are available for your type of lymphoma
- how well you coped with the treatment
- how quickly your lymphoma came back
- your age
- how fit you are.

Your medical team might discuss several different treatment options with you. Low-grade lymphoma grows slowly and you don’t usually need to start treatment urgently.
Active monitoring (‘watch and wait’)

If your lymphoma is growing slowly and isn’t causing any serious problems, your medical team might suggest a period of active monitoring (page 58). If you develop troublesome symptoms or your lymphoma starts to affect your major organs, you are likely to start treatment.

More chemo-immunotherapy

Many people with low-grade non-Hodgkin lymphoma that has come back or has not responded to treatment have more chemo-immunotherapy.

If you responded well to your last treatment and you had a long-lasting remission, you might have the same regimen you had the first time. However, it might not work as well or for as long a second time. If you didn’t respond well to your first treatment or you had a short remission, you are likely to have a different regimen.

For some types of lymphoma, you might have maintenance therapy after your chemo-immunotherapy (page 81), if you have not had it before.
Targeted therapies

Targeted therapies are available on the NHS or through clinical trials to treat some types of relapsed or refractory lymphoma.


Lenalidomide

Lenalidomide is a targeted therapy that helps your immune system attack lymphoma cells and stop them growing.

You might be offered lenalidomide, in combination with rituximab, if you have relapsed or refractory follicular lymphoma (page 145). This combination is sometimes called R², after rituximab and Revlimid (the brand name for lenalidomide).

Lenalidomide is also licensed to treat relapsed or refractory mantle cell lymphoma, but at the time of writing, it is not available on the NHS for this use.

You take lenalidomide as oral capsules once a day for the first 21 days of each 28 day treatment cycle. You have up to 12 cycles unless your lymphoma stops responding or you develop troublesome side effects.
Idelalisib

Idelalisib targets a protein called ‘PI3K’ on the surface of B cells. This blocks the signals that help B cells stay alive and divide. Blocking these pathways can make lymphoma cells die.

You might be offered idelalisib if you have follicular lymphoma (page 145) that has relapsed more than once. At the time of writing, it is available on the NHS in Scotland but it is not currently available on the NHS in other parts of the UK.

You take idelalisib as an oral tablet twice a day. You carry on taking it unless your lymphoma stops responding or you develop troublesome side effects.

Ibrutinib

Ibrutinib blocks a protein called ‘BTK’ on the surface of B cells. This can make lymphoma cells die or stop them dividing.

You might be offered ibrutinib if you have relapsed or refractory mantle cell lymphoma (page 146) or Waldenström’s macroglobulinaemia (page 153).

You take ibrutinib as an oral tablet once a day. You carry on taking it unless your lymphoma stops responding or you develop troublesome side effects.
**Stem cell transplant**

If your lymphoma came back quickly after your last treatment and you respond well to more treatment, your medical team might suggest that you have a **stem cell transplant** (page 78) to help your **remission** last as long as possible.

**Radiotherapy**

If your lymphoma is causing problems in one particular area of your body, you might be offered **radiotherapy** to the affected area (page 75) to help control your symptoms.

**Clinical trials**

You might be able to access new, experimental treatments for non-Hodgkin lymphoma by taking part in a clinical trial. If you consider entering a clinical trial, your medical team will talk to you about it in detail.

For information about clinical trials, or to search for a trial that might be suitable for you, visit lymphoma-action.org.uk/TrialsLink

We also produce a book about clinical trials. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.
What happens if lymphoma relapses again?

Many people with low-grade non-Hodgkin lymphoma relapse more than once. You are likely to receive a number of different treatments over the course of your lymphoma, which aim to keep it under control.

The treatment options for low-grade non-Hodgkin lymphoma that has relapsed again are similar to those used for first relapse. If you relapse several times in a short space of time, your medical team might recommend a more intensive approach, such as a stem cell transplant (page 78).

If your lymphoma comes back repeatedly, your treatment options are more limited because it is unlikely that the treatment you’ve had before will be beneficial. Together, you and your medical team may decide whether to continue with treatment or whether to concentrate on your quality of life. There are lots of palliative care options to control your symptoms and to keep you well (and out of hospital) for as long as possible.
It was clearly explained to me that the drug was being trialled and that it was impossible to know at that stage if it was the best course of treatment, although the clinical team seemed to think it would be. But they stressed it had to be my decision.

Sue, who took part in a clinical trial for relapsed follicular lymphoma in 2010.

Summary

• Refractory lymphoma is lymphoma that does not respond to your first treatment.
• Relapsed lymphoma is lymphoma that responds to treatment but then comes back.
• Most types of low-grade non-Hodgkin lymphoma relapse at some point, but it might not be for many years.
• There are several treatment options for relapsed or refractory low-grade non-Hodgkin lymphoma.
• Most people have a number of different treatments over the course of their lymphoma.
• Your doctor might ask you if you’d like to take part in a clinical trial.
I have check-ups every 4 months and I know to look out for lumps, tiredness, sweats and stomach problems. The best piece of advice I was given was, ‘Listen to your body.’

Pat, diagnosed with follicular lymphoma, age 56
What happens after treatment?

How you might feel after treatment 124
Follow-up 125
Late effects of treatment 129
How you might feel after treatment

You might expect to feel happy and relieved when you finish treatment but many people have mixed feelings. You might feel anxious and low. This can come as a surprise. It might be because:

• you only start to think deeply about what has happened once your treatment has finished
• you’re having to make changes to your life because of your lymphoma or its treatment
• you miss the reassurance of frequent contact with your hospital team
• you are worried about the future.

It is important to realise that these feelings are all natural, even if others expect you to feel happy. Talk to people, including your GP and medical team, about how you are feeling.

If you’d like to talk about how you’re feeling, call our Helpline (freephone) on 0808 808 5555 (see page 159).

My attitude to things changed. In the past I may have passed a restaurant and thought it might be nice to go sometime – now I book it. I dress up more, and don’t keep things for ‘best’. I grab every opportunity to have ‘bucket list’ moments.

Caroline, diagnosed with follicular lymphoma in 2006
Follow-up

When you finish treatment, you have an appointment with your medical team to talk about your physical, emotional and social needs. This is called a ‘holistic needs assessment’ or HNA. Your team uses it to create a care and support plan that’s specific to you. They also complete a treatment summary to give to you and your GP. It contains information about:

• the treatment you had
• any long-term effects it might have
• what symptoms to look out for after treatment
• who to contact if you notice them
• your follow-up plan.

You should also have a cancer care review with your GP or practice nurse. As well as your medical needs, this should cover any financial support you’re entitled to and information and support services you can access.

You should also be offered the chance to attend a health and wellbeing event to help you live well after treatment.

Lymphoma Action’s Live your Life workshops offer practical advice on how to stay healthy and active with and beyond cancer. For more information visit lymphoma-action.org.uk/live-your-life
Follow-up appointments

You are likely to have a follow-up appointment with your lymphoma team every 2 to 3 months at first. After a while, your appointments usually become less frequent.

How long your follow-up continues depends on your symptoms and the treatment you’ve had. Many people are followed-up for the rest of their lives. This is usually through regular, pre-booked appointments, but some centres use a system where you book your own appointments as-and-when you feel you need one. Your medical team tell you what to look out for and when to contact them. You might have regular blood tests, and your GP or medical team monitor the results.

You can contact your medical team at any time. Don’t wait until your next appointment if you are worried about your lymphoma.

Your GP should have a record of your diagnosis and all the treatment you’ve had, but it’s a good idea to remind them that you’ve had lymphoma treatment if you have an appointment with them for another reason.

Your follow-up appointments are to monitor your recovery, check that your lymphoma has not come back and to look out for late effects (page 129).
At your follow-up appointments, you might see your consultant, clinical nurse specialist, or another member of your medical team. They talk to you about how you’re feeling, any side effects you have and how you’re adjusting to life after treatment. They might examine you and take some blood tests. You’re not likely to have a scan unless there’s a particular reason.

You might feel anxious before your follow-up appointments. They are an inevitable reminder of your lymphoma at a time when you are trying to move on. **Remember that if you have no new symptoms, it is unlikely your lymphoma has come back.**

Before your appointment, write down any concerns or questions you’d like to discuss with your medical team.
Questions to ask about follow-up

• How often will I have appointments?
• Will I have any tests in between my appointments?
• Does my hospital offer a self-management system? If so, how does it work?
• Is there anything I should look out for?
• How will I know if the lymphoma has come back?
• Who do I contact if I have any concerns?
• How long will I be followed up for?

“

My last chemotherapy was 13 years ago and check-ups are now annual. I’ve been lymphoma-free for 13 years and I’ve done things I could barely have dreamed of before I was diagnosed. Getting older really is a privilege, and I am grateful to be able to look forward to the next stage in my life.

Caroline, diagnosed with follicular lymphoma in 2006
Late effects of treatment

Late effects are health problems that can develop months or years after treatment for lymphoma. Most people with low-grade non-Hodgkin lymphoma have few late effects.

The risk of developing late effects might seem worrying, but knowing what conditions you might be at risk of gives you the best chance of preventing late effects or getting treatment early if they develop.

We cover the most common late effects of lymphoma treatment in the next few pages. Your medical team should talk to you about the possible late effects of your treatment before it starts.

Questions to ask about late effects

- What late effects might I develop?
- How will I be monitored for these effects?
- How can I reduce my risk of being affected?
- What signs should I look out for?
- Are there any screening programmes I should take part in?
Lung problems

Radiotherapy to your chest can cause scarring of your lungs. If you are affected, you might not be able to do as much exercise as you used to before you feel out of breath.

Heart problems

Radiotherapy to your chest and some chemotherapy drugs can damage your heart. This includes doxorubicin, a component of CHOP (page 68).

People who have been treated for lymphoma also have a higher than usual chance of developing ‘metabolic syndrome’ – a combination of diabetes, high blood pressure and obesity. This also increases your risk of developing heart disease.

Heart problems generally start 10 years or more after treatment but they can develop sooner. Symptoms can include swollen ankles or feeling out of breath more easily than usual (for example, when walking up steps).

You can reduce your risk of heart disease by looking after your blood pressure and cholesterol level, keeping active, and avoiding smoking or excessive alcohol use.

Visit bhf.org.uk for information about heart problems and tips on keeping your heart healthy.
Other cancers

Treatment for low-grade non-Hodgkin lymphoma can increase your risk of developing another cancer in the future. This risk is small. Most people who have been treated for lymphoma never develop another cancer because of the treatment they had.

The type of cancer you might be at risk of depends on the treatment and dose you had, how old you were when you were treated and how old you are now. Your medical team can advise you on the types of cancer you might be at risk of and the signs to look out for. People might still develop unrelated cancers as they get older.

Underactive thyroid gland

If you’ve had radiotherapy to your neck, your thyroid gland might become underactive (known as ‘hypothyroidism’). This makes the cells in your body slow down. It can make you feel very tired and be more sensitive to cold. You might also put on weight. It can be diagnosed by a simple blood test at your GP surgery and is easily treated with tablets.

Effects on fertility

Some chemotherapy drugs or radiotherapy to your tummy (abdomen) or the area below your belly button (your pelvis)
can affect your ovaries or testicles. This might lead to early menopause in women, and reduced fertility in both men and women.

Different treatments have different effects on your fertility. Your medical team should tell you if your treatment is likely to affect your fertility. If it is, and you think you might want to have children in the future, they can refer you to a fertility specialist to discuss options for preserving your fertility before you start treatment for lymphoma.

We have more information on early menopause and reduced fertility after lymphoma treatment at lymphoma-action.org.uk/SideEffects

Tips to lower your risk of late effects

• If you are a smoker, try to give up.
• Find out what late effects you are at risk of and know what symptoms to look out for.
• Attend your follow-up appointments.
• Go to any health screening programmes you’re invited to take part in.
• Eat a healthy diet and maintain a healthy weight.
• Stay active.
• Protect your skin from the sun.
Summary

• It is natural to experience mixed feelings when you finish treatment.
• You have follow-up appointments to monitor your recovery, check your lymphoma has not come back and to look out for late effects.
• Late effects are health problems that can develop months or years after treatment for lymphoma. It is important to know what late effects you’re at risk of.
• Possible late effects of lymphoma treatment include lung problems, heart problems, other cancers, underactive thyroid, reduced fertility and early menopause.
I found myself trying various things to assist my recovery, such as relaxation and meditation, green tea, cutting out caffeine, various vitamin supplements, and eating organic food. I don’t know whether these things helped, but it made me feel I was doing something proactive.

Caroline, diagnosed with follicular lymphoma, age 40
Living with and beyond low-grade non-Hodgkin lymphoma

Your feelings 136
Healthy living 138
When someone close to you has lymphoma 139
Your feelings

No one can tell you exactly how you will feel when you are diagnosed with low-grade non-Hodgkin lymphoma, during active monitoring, when you have treatment or afterwards. You will probably have different feelings at different times. You might feel:

- shocked – you might feel numb and find it hard to accept things at first
- sad – your life and plans, at least for a while, are going to have to change
- scared – often this is fear of the unknown, so finding out more about what to expect can help
- angry – you might feel you’ve lost control of your life and resent that this has happened to you.

These feelings are natural. It can help to talk about them, especially if you are finding it hard to cope.

Talking to people closest to you can sometimes be difficult, particularly if they are dealing with their own feelings about your illness. Your specialist nurse or GP is often a good person to talk to if you’re looking for help.

Our Helpline Services (page 159) offer emotional support if you, or any of your family or friends, want to talk to someone about your lymphoma.
Depression

You might feel there are times when you don’t want to talk to anyone and just want to be alone. It is not unusual to feel low from time-to-time but if you feel like this a lot of the time, you might be experiencing depression.

People who are affected by depression might feel hopeless, guilty or worthless. They might lose interest in hobbies or everyday activities, or find it difficult to concentrate on things. They might have trouble sleeping, sleep more than usual, or lose their appetite.

**If you, or those around you, think you might be affected by depression, talk to someone.** Your medical team or GP are good first contacts. There is a lot of support, treatment and counselling available for people with depression. Most oncology units offer specialist psychology services.

Visit nhs.uk/Moodzone for tips to help you cope with depression, anxiety and stress, or nhs.uk/oneyou/every-mind-matters for tips, tools and apps to help you look after your mental health.

Mind (mind.org.uk) have lots of information on mental health and where you can seek support.

If you are in crisis, call the Samaritans on 116 123.
Healthy living

Many people find that having cancer makes them think about their lifestyle. Changes that you make after your diagnosis could help you to live a longer and healthier life after treatment.

I am a fairly fit person and used to run and cycle. Once I was out of hospital, I started walking, increasing my distance each day very slowly. Within 2 to 3 months of the stem cell transplant I felt pretty much back to normal.

Stephen, diagnosed with mantle cell lymphoma in 2016

It is important that you:

• eat a healthy diet
• keep a healthy weight
• don’t smoke
• exercise regularly
• keep up-to-date with your vaccinations, including the annual flu vaccine
• take part in any health screening programmes you are invited to attend.

We have more on living with and beyond lymphoma, including information on diet, exercise, vaccinations and travel insurance. We also have a book called *Living with lymphoma*. To learn more, visit lymphoma-action.org.uk/LWL
When someone close to you has lymphoma

When someone close to you has lymphoma, it can be a difficult time for you, too. You might feel helpless watching someone you love going through tests and treatments and being unsure of what the future holds. You might not know how best to support them – but there are lots of things you can do.

"My husband was my emotional support. When I cried, he cried; when I was angry, he was angry. He took advantage of the counselling offered at the hospital about caring for someone with a chronic disease, which he found really valuable. My son was unbelievably practical and, between them, I felt I had the perfect balance.
Debbie, diagnosed with follicular lymphoma, age 45"

Don’t forget to take care of yourself. If you become run down or ill, you will not be able to support your loved one. Make sure you look after your own health, eat well and get plenty of rest.

You probably have many of the same emotions as your loved one. Talk to someone – friends, family, or a specialist – especially if you are finding it hard to cope.
People are often unsure what to say to someone affected by cancer or worry that they might say the wrong thing. Often, you don’t need to say anything – a smile or a hug may say much more. Let the person with lymphoma know that you love them. Just being ready to listen can be a huge help.

Things you can do to help your loved one include:

- providing transport to and from hospital
- going with them to their appointments
- helping with shopping or preparing meals
- taking care of other family members
- encouraging them to spend time seeing other people or doing things they enjoy
- organising things to do when they feel up to it.

If you’re looking after a relative or a friend with lymphoma, you are a carer. You might be entitled to financial support. Carers UK (carersuk.org) and Carers Trust (carers.org) are helpful sources of support and practical information.
Summary

• You might experience a mix of emotions at different times during your experience of lymphoma. This is normal.
• If you feel down a lot of the time, it could be a sign of depression. Talk to your GP to find out about support available to you.
• Try and live a healthy lifestyle, following a healthy diet and exercising regularly.
• You might find it useful to learn about your type of lymphoma and the treatments you’ve had.
• If you are caring for someone with lymphoma, remember to look after yourself, too.
A bit of investigation on the Lymphoma Action website quickly made me realise that lymphoma isn’t just one cancer; there are many different types, with different treatments.

Stephen, diagnosed with mantle cell lymphoma in 2016, age 63
Types of low-grade non-Hodgkin lymphoma

- Follicular lymphoma 145
- Mantle cell lymphoma 146
- Marginal zone lymphomas 148
  - MALT lymphoma 148
  - Nodal marginal zone lymphoma 151
  - Splenic marginal zone lymphoma 152
- Waldenström’s macroglobulinaemia (lymphoplasmacytic lymphoma) 153
Low-grade non-Hodgkin lymphoma

It is important for your medical team to find out what type of lymphoma you have so that you can have the most appropriate treatment.

You might want to read only the section on your own type of lymphoma. If you are not sure exactly what kind of lymphoma you have, ask your doctor or nurse.

We have not been able to include every type of low-grade non-Hodgkin lymphoma. Some types have more than one name, so check with your medical team in case we have listed your type under another name. If not, they might be able to tell you if we have included a lymphoma similar to yours, or advise you on where you can get more information.

We have more detailed information on most of the different types of low-grade non-Hodgkin lymphoma. View or download our information sheets at lymphoma-action.org.uk/NHL or call 0808 808 5555 to request a copy.

We also produce separate information on skin lymphomas, which are often treated differently from other types of lymphoma. Visit lymphoma-action.org.uk/SkinLymphoma or call 0808 808 5555 for more information.
Follicular lymphoma

Follicular lymphoma is the most common type of low-grade non-Hodgkin lymphoma. It is called ‘follicular’ because the abnormal cells usually develop in clumps called ‘follicles’. It can develop at any age, but it is more common in people over 60.

**Symptoms:** Symptoms of follicular lymphoma usually develop gradually. The most common symptom is a lump or several lumps, often in the neck, armpit or groin. Most people have no other symptoms.

**Treatment:** If your lymphoma is growing slowly and is not causing problems, you are likely to have active monitoring (‘watch and wait’; page 58) or a course of rituximab (page 71). Most people who need treatment have chemo-immunotherapy (page 72). You might have radiotherapy (page 75) if your lymphoma is only affecting one part of your body. After treatment, most people have maintenance therapy (page 81).

If follicular lymphoma relapses, treatment options include more chemo-immunotherapy (page 72), lenalidomide plus rituximab (page 117), or idelalisib (page 118). You might also have more maintenance therapy. If your lymphoma relapses very quickly, your medical team might recommend a stem cell transplant (page 78).
Mantle cell lymphoma

Mantle cell lymphoma develops from B cells. It is called ‘mantle cell’ because the cells come from a region of the lymph nodes called the ‘mantle zone’. Although doctors consider it to be a type of low-grade lymphoma, it can also grow quickly.

It develops most often in people in their 60s. It is more common in men than women.

**Symptoms**: Mantle cell lymphoma usually causes swollen lymph nodes but it has often spread to other areas of the body by the time it is diagnosed. It can affect the bone marrow, bloodstream, bowel, spleen or tonsils.

**Treatment**: If your lymphoma is growing slowly and is not causing problems, you might be put on active monitoring (‘watch and wait’; page 58). Otherwise, if you are fit enough, you are likely to have a chemo-immunotherapy regimen that includes a drug called cytarabine, followed by an autologous stem cell transplant (page 78) to make your remission last longer. After treatment, most people have rituximab maintenance therapy (page 81).
If a stem cell transplant is not suitable, you might have a different chemo-immunotherapy regimen such as R-CHOP or bendamustine plus rituximab. People with localised disease might have radiotherapy (page 75).

If your mantle cell lymphoma relapses, you are likely to be offered ibrutinib (page 118) or more chemo-immunotherapy. Some people have an allogeneic stem cell transplant if they are fit enough, although this is uncommon.

My diagnosis was mantle cell lymphoma stage 3 with my lymph nodes and spleen affected. I now realise that at the age of 63 and a man, I am the classic profile of someone with this type of lymphoma.

Stephen, diagnosed with mantle cell lymphoma in 2016
Marginal zone lymphomas

Marginal zone lymphomas develop from B cells. They are called ‘marginal zone’ because they develop in a region at the edge of lymphoid tissues (collections of lymphocytes) known as the marginal zone.

There are three types of marginal zone lymphoma:

- MALT lymphoma, which develops in lymphoid tissues outside lymph nodes
- nodal marginal zone lymphoma, which develops in lymph nodes
- splenic marginal zone lymphoma, which develops in the spleen.

MALT lymphoma

MALT lymphoma is also known as ‘extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue’. Mucosa-associated lymphoid tissue (MALT) refers to collections of lymphocytes in your mucosa (the moist, protective layer of cells that lines many parts of your body, such as your mouth, gut, airways and some internal organs).

MALT lymphomas are normally divided into gastric (stomach) MALT lymphoma and non-gastric MALT lymphoma.
**Gastric MALT lymphoma**

Gastric MALT lymphoma develops in the stomach. It is strongly linked to infection with bacteria called *Helicobacter pylori* (*H. pylori*). This is a very common infection, which doesn’t usually cause serious problems. Most people with *H. pylori* infection do not develop lymphoma.

**Symptoms:** Persistent indigestion is usually the only symptom of MALT lymphoma. Some people might have tummy pain, sickness, weight loss or anaemia. Some people don’t have any symptoms at all.

**Treatment:** Clearing the *H. pylori* infection with antibiotics and acid-reducing medication also clears the lymphoma in most people. You might need several courses of treatment to clear the infection. If this does not get rid of your lymphoma, you might need radiotherapy (page 75), or chemo-immunotherapy (page 72). If your lymphoma is not causing problems, you might have a period of active monitoring (page 58).

If your lymphoma relapses, the same treatments are usually successful again. You might be asked if you’d like to take part in a clinical trial (page 119).
Non-gastric MALT lymphoma

Non-gastric MALT lymphoma develops in areas where MALT tissue has formed in response to inflammation. It is linked to infections with certain bacteria or particular autoimmune conditions (when your immune system mistakenly attacks your own body).

**Symptoms:** Most people have no symptoms at all and the lymphoma is found during tests to investigate something else. If symptoms develop, they depend on where the lymphoma is growing. It most commonly affects the spit (salivary) glands, thyroid, lungs, skin, gut (bowel) or tissues around the eye.

**Treatment:** If your lymphoma is not causing problems, you might have a period of active monitoring (‘watch and wait’; page 58). If it is linked to an infection, clearing the infection with antibiotics might also clear the lymphoma. Some people with non-gastric MALT lymphoma need radiotherapy (page 75) or chemo-immunotherapy (page 72).

If your lymphoma relapses, you might be asked if you’d like to take part in a clinical trial (page 118) or you might have more chemo-immunotherapy.
Nodal marginal zone lymphoma

Nodal marginal zone lymphoma develops in lymph nodes. It can occur at any age but is most common in people over 50. It is sometimes linked to hepatitis C virus infection.

**Symptoms:** Most people have swollen lymph nodes, typically in the neck but they can develop in other places. This is usually the only symptom. Some people feel very tired and a few have B symptoms.

**Treatment:** If your lymphoma is not causing problems, you are likely to have active monitoring (‘watch and wait’; page 58). If you have hepatitis C virus infection, clearing the infection with antiviral medication might clear the lymphoma. If you need other treatment, you might have radiotherapy (page 75) if your lymphoma is only affecting one part of your body. Most people who need treatment have chemo-immunotherapy (page 72).

If your lymphoma relapses, you might be asked if you’d like to take part in a clinical trial (page 118) or you might have more chemo-immunotherapy. Rarely, if your lymphoma relapses very quickly, your medical team might recommend a stem cell transplant (page 78).
Splenic marginal zone lymphoma

Splenic marginal zone lymphoma is a rare type of lymphoma that develops in your spleen. It can affect people of any age but is most common in people in their 60s. Some cases are linked to certain infections and autoimmune conditions.

**Symptoms:** Most people have an enlarged spleen, which might cause discomfort in your tummy or chest, or a feeling of being full very quickly after eating. Some people have low blood counts or symptoms caused by abnormal antibodies, such as poor circulation or a rash in cold weather.

**Treatment:** If your lymphoma is not causing problems, you are likely to have active monitoring ('watch and wait'; page 58). If you have hepatitis C virus infection, clearing the infection with antiviral medication might clear the lymphoma. If you need other treatment, you are likely to have antibody therapy (page 71) on its own or combined with chemotherapy (page 61). If the lymphoma is in one part of your body, you might have radiotherapy. Rarely, if your spleen is very large, you might need an operation to remove it (a splenectomy).

If your lymphoma relapses, you might be invited to take part in a clinical trial (page 119) or you might have more chemo-immunotherapy.
Waldenström’s macroglobulinaemia (lymphoplasmacytic lymphoma)

Lymphoplasmacytic lymphoma (LPL) is a rare lymphoma that develops from B cells that are actively making antibodies. It is most common in people over 65. It affects more men than women. Almost all cases of LPL are a type called Waldenström’s macroglobulinaemia (WM).

**Symptoms:** The symptoms of WM are very variable. You might have low blood counts or symptoms caused by abnormal antibodies, which can make your blood too thick. This can cause nosebleeds, vision changes, dizziness or headaches, drowsiness, poor concentration, confusion and shortness of breath. Swollen lymph nodes and B symptoms are less common than with other types of lymphoma.

**Treatment:** If your lymphoma is not causing problems, you are likely to have active monitoring (page 58). If you need treatment, you are likely to have chemo-immunotherapy (page 72). You might also need plasmapheresis (page 84) if you have high levels of abnormal antibodies in your blood.

If your lymphoma relapses, you might have a further period of active monitoring (page 58), more chemo-immunotherapy (page 72) or ibrutinib (page 118). Rarely, if WM relapses very quickly, your medical team might recommend a stem cell transplant (page 78).
**Glossary**

**Active monitoring**  
a period when you have regular check-ups to monitor how your lymphoma is affecting you before you start treatment; also called ‘watch and wait’

**Allogeneic**  
tissues or cells that come from a donor, rather than from you

**Anaemia**  
shortage of red blood cells or haemoglobin in the blood

**Anaesthetic**  
a drug given to numb part of your body (local anaesthetic) or to put your whole body into a sleep-like state (general anaesthetic)

**Antibody**  
a protein made by white blood cells that recognises and sticks to things that don’t belong in your body, such as viruses or bacteria

**Antibody therapy**  
treatment that uses antibodies made in a laboratory to target cancer cells

**Autologous**  
the use of your own tissues or cells, rather than a donor’s
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>B symptoms</strong></td>
<td>fever (temperature above 38°C), night sweats and unexplained weight loss</td>
</tr>
<tr>
<td><strong>Bone marrow</strong></td>
<td>the spongy material at the centre of larger bones where blood cells are produced</td>
</tr>
<tr>
<td><strong>Chemo-immunotherapy</strong></td>
<td>chemotherapy combined with antibody therapy</td>
</tr>
<tr>
<td><strong>Chemotherapy</strong></td>
<td>treatment that uses drugs to kill cancer cells; ‘chemo’ for short</td>
</tr>
<tr>
<td><strong>Chemotherapy regimen</strong></td>
<td>a combination of chemotherapy drugs given at a particular dose and schedule</td>
</tr>
<tr>
<td><strong>Cycle</strong></td>
<td>a round of treatment followed by a rest period to allow your body to recover before the next round of treatment</td>
</tr>
<tr>
<td><strong>Immune system</strong></td>
<td>the system in your body that fights off and prevents infection</td>
</tr>
<tr>
<td><strong>Immunotherapy</strong></td>
<td>treatment that helps your immune system recognise and destroy cancer cells</td>
</tr>
<tr>
<td><strong>Late effects</strong></td>
<td>side effects that can develop months or years after treatment</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
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<tr>
<td>---------------------------</td>
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</tr>
<tr>
<td>Lymph nodes</td>
<td>small, bean-shaped structures spread throughout your lymphatic system that filter lymph</td>
</tr>
<tr>
<td>Lymphatic system</td>
<td>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</td>
</tr>
<tr>
<td>Lymphocytes</td>
<td>specialised white blood cells that are part of your immune system; the cells that become cancerous in lymphoma</td>
</tr>
<tr>
<td>Lymphoid tissue</td>
<td>a collection of lymphocytes</td>
</tr>
<tr>
<td>Maintenance therapy</td>
<td>treatment to keep lymphoma in remission for as long as possible</td>
</tr>
<tr>
<td>Neutrophils</td>
<td>a type of white blood cell that is important in fighting infections</td>
</tr>
<tr>
<td>Peripheral neuropathy</td>
<td>damage to the nerves of your peripheral nervous system, which carries signals between different parts of your body</td>
</tr>
<tr>
<td>Platelets</td>
<td>tiny fragments of cells in your blood that help your blood clot</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>treatment that uses radiation to kill cancer cells</td>
</tr>
<tr>
<td><strong>Red blood cell</strong></td>
<td>the type of blood cell that carries oxygen around your body</td>
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<tr>
<td>-------------------</td>
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<tr>
<td><strong>Refractory lymphoma</strong></td>
<td>lymphoma that doesn’t respond to treatment</td>
</tr>
<tr>
<td><strong>Relapsed lymphoma</strong></td>
<td>lymphoma that comes back after treatment</td>
</tr>
<tr>
<td><strong>Remission</strong></td>
<td>no evidence of disease on tests or scans; ‘partial’ remission means the disease has reduced but not gone completely</td>
</tr>
<tr>
<td><strong>Spleen</strong></td>
<td>a pear-sized organ behind your ribcage on the left-hand side; it filters blood</td>
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<tr>
<td><strong>Stage</strong></td>
<td>a measure of how much of your body is affected by lymphoma</td>
</tr>
<tr>
<td><strong>Stem cells</strong></td>
<td>undeveloped cells that can mature into many different cell types; ‘haematopoietic’ stem cells mature into different types of blood cell</td>
</tr>
<tr>
<td><strong>Stem cell transplant</strong></td>
<td>a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells</td>
</tr>
<tr>
<td><strong>Steroid</strong></td>
<td>a medicine with anti-cancer effects that also affects your body’s response to infection and injuries</td>
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<tr>
<td><strong>Targeted therapies</strong></td>
<td>drugs that interfere with particular proteins or biological processes in cancer cells to stop them growing or dividing</td>
</tr>
<tr>
<td><strong>Thymus</strong></td>
<td>a small, butterfly-shaped gland behind your breastbone where T lymphocytes develop</td>
</tr>
<tr>
<td><strong>Thyroid gland</strong></td>
<td>a gland at the front of your neck that produces a hormone called thyroxine, which controls how fast the cells in your body work</td>
</tr>
<tr>
<td><strong>Transfusion</strong></td>
<td>having blood or blood products given to you through a drip into a vein</td>
</tr>
<tr>
<td><strong>White blood cell</strong></td>
<td>a cell that helps your body fight infections; there are several different types, including lymphocytes and neutrophils</td>
</tr>
</tbody>
</table>
Information and support

If you’d like to talk to someone about anything to do with lymphoma, get in touch.

Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm, on 0808 808 5555. You can also use Live Chat on our website.

Come to one of our **Support Groups**. Find one near you at lymphoma-action.org.uk/SupportGroups.

Use our **Buddy Service** to share experiences with someone in a similar situation to you. Call our Helpline for details.

Visit lymphoma-action.org.uk/**TrialsLink** to search for clinical trials that might be suitable for you.

Check out our **YouTube channel** to watch personal stories and medical films.

See our website for full details of our services. For our latest news and updates, follow us on social media:

- [Facebook](#) (@LymphomaAction)
- [Twitter](#)
- [Instagram](#) (lymphoma_action)
If you’re interested in finding out more about any of the topics in this book, we have lots more information available on our website.

We also produce a number of books, which are available free of charge. In particular, you might find the following books helpful:

• Active monitoring (watch and wait) for lymphoma
• Clinical trials for lymphoma
• Living with and beyond lymphoma

Find our full range of books and information, including accessible information and Easy Reads, at lymphoma-action.org.uk/Books or call 0808 808 5555 for more information.

Our information is evidence-based, approved by experts and reviewed by users. 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
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 try to improve our resources and are interested in any feedback you might have. 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 us on 0808 808 5555.

References

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

**Blood Cancer UK** provides information about blood cancers, including stem cell transplants.
0808 2080 888  www.bloodcancer.org.uk

**British Association for Counselling and Psychotherapy** provides a list of accredited counsellors in your area.
01455 883300  www.bacp.co.uk

**Cancer Research UK** offers information on all types of cancer, a searchable database of clinical trials and a helpline staffed by nurses.
0808 800 4040  www.cancerresearchuk.org

**Carers UK** offers expert advice, information and support for carers.
0808 808 7777  www.carersuk.org

**Citizens Advice** helps people resolve legal, money, housing, consumer and other problems by providing free, independent and confidential advice.
03444 111 444  www.citizensadvice.org.uk

**Leukaemia Care** provides information, advice and support for anyone affected by blood cancer.
08088 010 444  www.leukaemiacare.org.uk
Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.
0808 808 0000 www.macmillan.org.uk

Maggie’s Centres provides free practical, emotional and social support to people with cancer and their family and friends.
0300 123 1801 www.maggies.org

WMUK provides information and support for people with Waldenström’s macroglobulinaemia.
020 3096 7858 www.wmuk.org.uk

Working with Cancer provides advice about remaining in work, returning to work or finding work for people with cancer.
07919 147784 www.workingwithcancer.co.uk

Visit lymphoma-action.org.uk/UsefulOrgs for a list of other organisations you might find helpful.
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The information in this book can be made available in large print.
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Lymphoma Action is the UK’s only charity dedicated to lymphoma, the fifth most common cancer. Our mission is to make sure no one faces lymphoma alone.

Helpline (freephone) 0808 808 5555 (Mon to Fri, 10am to 3pm)
Email information@lymphoma-action.org.uk
Visit www.lymphoma-action.org.uk
Live Chat via our website (Mon to Fri, 10am to 3pm)