High-grade non-Hodgkin lymphoma

- Diffuse large B-cell lymphoma
- Burkitt lymphoma
- Double-hit and triple-hit lymphoma
- Central nervous system lymphoma
- Other high-grade B-cell lymphomas
- T-cell lymphomas
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

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**Key contact**

Name:  

Role:  

Contact details:  

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<thead>
<tr>
<th>Job title/role</th>
<th>Name and contact details</th>
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<tr>
<td>GP</td>
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About this book

High-grade (or aggressive) 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 high-grade non-Hodgkin lymphoma is and how it is diagnosed and treated. It includes tips on coping with treatment and 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.

This book uses some scientific words. Words that are in **bold** are explained in the glossary on pages 152 to 156.

Special thanks to Bernard, Ian, Jennie, Kat, Kathleen, Martin, Miriam, Nicola, Richard, Roger, Ros and Tracey for sharing their experiences throughout this book.
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Non-Hodgkin lymphoma is an odd one, as I have found you don’t fit a profile. It’s not mentioned on TV and it doesn’t have the PR, so people don’t understand.

Ros, diagnosed with diffuse large B-cell lymphoma at 56
Introduction to lymphoma

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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 uncontrolled 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 or other parts of your body, usually in lymph nodes 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.
Introduction to lymphoma

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-url)

| Normal cell | Cancer cell | Cancer cells divide to make more cancer cells | Mass of cancer cells |

**Figure: How cancer develops**
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 heard of lymphoma, but thought there were just two types. What I found when I searched on the internet was just baffling – there was a list of different types as long as my arm.

Jennie, diagnosed with Burkitt lymphoma at 27
Summary

- Lymphoma is a type of blood cancer.
- Lymphoma develops when white blood cells called lymphocytes grow out of control.
- There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma.
My consultant explained that there had not been many studies done in my type of lymphoma yet, and that information on it on the internet might well just be discouraging and unhelpful. The conversation with him was reassuring – he explained my condition and filled me with a lot more confidence.

Kat, diagnosed with double-hit lymphoma, age 32
High-grade non-Hodgkin lymphoma

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What is high-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. This might sound worrying, but fast-growing cells are often more sensitive to treatment than slow-growing cells. Many high-grade lymphomas respond very well to treatment.

B-cell or T-cell lymphoma

There are two main types of lymphocyte: B lymphocytes (B cells) and T lymphocytes (T cells). In healthy people, they work in different ways to protect your body from infection and illness.
• T cells recognise and target 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.
• Non-Hodgkin lymphomas that develop from T cells are called T-cell 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 high-grade non-Hodgkin lymphoma in the last chapter of this book (pages 133 to 151).**

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

Almost 14,000 people are diagnosed with non-Hodgkin lymphoma each year in the UK – around 38 people every day. About half of these people have high-grade non-Hodgkin lymphoma. Most of these are B-cell lymphomas. Only around 1 in 10 people with high-grade non-Hodgkin lymphoma have a T-cell lymphoma.

Most people who are diagnosed with non-Hodgkin lymphoma are over 55, but it can affect people of any age, including children and young people. Most cases are diagnosed 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.

Venturing into the unknown was frightening, especially when I was told I had a rare cancer that my medical team had not treated before. As for me, I had barely heard of the word ‘lymphoma’.

Kathleen, diagnosed with Burkitt lymphoma in 2006, age 60

We produce a Young person’s guide to lymphoma for 15 to 24-year-olds. Call 0808 808 5555 or visit lymphoma-action.org.uk for your copy.
What causes high-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.

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 HIV infection are more likely to develop lymphoma than other people (page 151). Lymphoma is also more common in people who are taking medicines that suppress their immune system (for example, after a transplant or for autoimmune or inflammatory conditions such as inflammatory bowel disease or rheumatoid arthritis). However, most people who have these conditions do not develop lymphoma.

Some types of lymphoma are linked to certain viruses or autoimmune conditions (when your immune system mistakenly attacks your own body).
Symptoms of high-grade non-Hodgkin lymphoma

High-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.

Swollen lymph nodes

The most common symptom of high-grade non-Hodgkin lymphoma is a swollen lymph node or nodes that don’t 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. The swollen nodes can form large lumps.

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

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

**Drenching sweats**: especially at night.

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

Lymphoma can develop anywhere in your body so it can cause many different symptoms. Some of the more common symptoms include:

- **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 very tired.
- **Difficulty shaking off infections**: your body is making abnormal lymphocytes, so there are not 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.

“I had felt tired and run down for a couple of months but put that down to working full time in a new job, and being a mum of a lively 6 year old.
Nicola, diagnosed with diffuse large B-cell lymphoma in 2017, age 44
Extranodal symptoms

Sometimes, lymphoma develops outside the lymph nodes. This is called ‘extranodal’ lymphoma. For example, it might develop in your gut, lungs, liver, 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
- headaches.

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

High-grade non-Hodgkin lymphoma generally responds well to treatment. It is usually treated with the aim of sending the lymphoma into complete remission (no evidence of lymphoma on tests and scans). This is sometimes known as treatment with ‘curative intent’.
Most people with high-grade non-Hodgkin lymphoma who go into remission are likely to stay in remission. Your doctor might not use the word ‘cure’ because this is difficult to know for certain. However, the longer you are in complete remission, the less likely your lymphoma is to come back.

In some people, lymphoma gets worse (progressive disease) or comes back after a period of remission (relapses). If this happens, other treatments are available. See page 105 for more information on lymphoma that comes back or doesn’t respond to treatment.

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
• how much lymphoma you have in your body and where it is (the stage of your lymphoma – see page 38)
• 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.
Summary

• High-grade non-Hodgkin lymphoma is a fast-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.
• High-grade non-Hodgkin lymphoma is usually treated with the aim of sending the lymphoma into complete remission.
What had started as backache and a lump in my armpit saw me referred to my local hospital.

I had a series of meetings with consultants and many tests later was told I had lymphoma, but that further tests were needed to identify the exact type. On 4 November 2006, I was diagnosed with Burkitt lymphoma, stage 4.

Kathleen, diagnosed with Burkitt lymphoma in 2006, age 60
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How is high-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. Most people who are referred to a cancer service do not have cancer.

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 and scans for lymphoma, but you might not need all of them.

For more information about any of the tests and scans visit lymphoma-action.org.uk/Tests
Lymph node biopsy

For most people, 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). 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 sample results usually take a week or more to come back. The results of more specialised tests can take longer and some people might need to start treatment before the results are finalised. When the results are available, your treatment might be modified.

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.

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

“I had an MRI and biopsy. I was told I definitely had cancer but it could either be tonsil cancer or lymphoma. Another week and a tonsillectomy later, I was told I had DLBCL, and another week and one PET scan later, that it was stage 4. The whole 4 week period was like being on a long haul flight going through turbulence. I’d be fine one minute then just feel physically terrified the next.”

Nicola, diagnosed with diffuse large B-cell lymphoma in 2017, age 44
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 an injection to help certain parts of your body show up better (a ‘contrast’ injection). 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 high-grade lymphoma have a PET scan to find out which parts of their body are affected by lymphoma. You usually have another one at the end of your treatment 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, tell your doctor. They will tell you how 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).

MRI scans

Magnetic resonance imaging (MRI) scans use strong magnets to take pictures of the inside of your body. You might have an MRI scan if you are allergic to the dye used in PET/CT scans, or if you have lymphoma in your brain. The MRI machine is a little noisy, but you are usually given headphones to help block the noise.

- Tell your medical team if you have a pacemaker or any metal implants such as joint replacements.
- Tell your medical team if you feel anxious about your MRI scan.
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 (page 32) and your blood tests to decide if you need a bone marrow biopsy.

This 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.

If you are very anxious, you might be able to have a sedative (a drug to help you relax).

Lumbar puncture

Some people with high-grade non-Hodgkin lymphoma might have suspected lymphoma cells in their brain or spinal cord (known as the **central nervous system**, or CNS). Your medical team might test this using a **lumbar puncture**.
A lumbar puncture involves taking a few drops of the fluid that surrounds your brain and spinal cord (called cerebrospinal fluid, or CSF) to be examined in a lab.

- You have a local anaesthetic to numb the skin over your lower spine. If you are very anxious, you might also have a sedative.
- You either lie on your side with your knees bent, or sit up with your arms over a table.
- A doctor puts a small needle into a gap between the bones in your lower back and removes a few drops of CSF.
- You might have a small amount of chemotherapy injected into your spinal fluid afterwards. Your doctor will tell you if you need this.

Figure: Having a lumbar puncture
A lumbar puncture takes about 5 to 10 minutes. You need to lie flat for about an hour afterwards. You might have a headache afterwards.

Drink plenty of water and take painkillers if you need them. Your medical team can advise you which type is best for you.

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 or sedative?
• Do I need to do anything to prepare for any of the tests and scans?
• Is there anything I need to be careful of afterwards?
• Can I drive? Can I go back to work straightaway?
• How long 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)?

Use our Helpline Services (see page 157 for details) or visit lymphoma-action.org.uk/Waiting for tips on how to cope with waiting for your test results.
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.
Sometimes letters are added to the stage.

<table>
<thead>
<tr>
<th>A</th>
<th>You don’t have any <strong>B symptoms</strong>.</th>
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<tbody>
<tr>
<td>B</td>
<td>You have one or more <strong>B symptoms</strong> (weight loss, night sweats or fevers).</td>
</tr>
<tr>
<td>E</td>
<td>You have lymphoma that started outside the lymphatic system (‘<strong>extranodal</strong>’ lymphoma). Extranodal lymphoma doesn’t include lymphoma that started in a lymph node and spread to a body organ.</td>
</tr>
<tr>
<td>X</td>
<td>At least one of your affected lymph nodes is very 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. **Unlike many other cancers, advanced stage lymphoma can be successfully treated.**

Ask your specialist if you’re not sure what stage your lymphoma is.
Summary

• High-grade non-Hodgkin lymphoma is usually diagnosed using a lymph node biopsy.
• You have other tests such as blood tests and a PET/CT scan to find out which parts of your body are affected by lymphoma (staging).
• The results of your tests and scans help your doctor plan the most suitable treatment for you.
I was told they needed to start treatment straightaway as the lymphoma was getting out of control. In less than 2 weeks I felt I had lost everything, but facing a life-threatening illness meant that I had no choice but to get on with it.

Jennie, diagnosed with Burkitt lymphoma, age 27
How is high-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). 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.

Many 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 it might be at a larger hospital with a cancer centre that’s further away. Sometimes people have their treatment shared between the two places.

I worried that my local hospital might be out of its depth with advanced cancer treatment, but I couldn’t have been more wrong. It was great to know all the nurses and feel they knew and cared for me.

Martin, diagnosed with diffuse large B-cell lymphoma in 2018, age 64

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? Does it have WiFi?
How does my medical team decide what treatment I need?

High-grade non-Hodgkin lymphoma is usually treated with the aim of sending it into complete remission. This means there is no sign of any lymphoma on tests or scans at the end of treatment. Your medical team chooses the treatment they think is most likely to achieve complete remission with the minimum possible side effects.

Your treatment is tailored to you. 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
- the stage of your lymphoma
- your symptoms
- your age
- any other health conditions you have
- your general fitness
- the treatment options that are available
- your feelings about your treatment options
- other factors that might be important to you in the future, such as having a family.

Let your medical team know if you have any strong views about your treatment.
If you have other health conditions, or are generally less fit, your doctor might suggest a gentler treatment or adapt standard treatment to make it safer for you.

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

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

Your doctors try to balance the risk of your lymphoma coming back against your risk of developing side effects and late effects (health problems related to lymphoma treatment that can 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.

The relationship I built with nursing staff, healthcare assistants, pharmacists and junior doctors, as well as the oncologists, was invaluable. On an informative and an emotional level they were always forthcoming.

Nicola, diagnosed with diffuse large B-cell lymphoma in 2017, age 44
Treatment options for high-grade non-Hodgkin lymphoma

Treatment for high-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:

• Most people with high-grade non-Hodgkin lymphoma have chemotherapy.
• If you have a B-cell lymphoma, you usually have an antibody therapy (for example, rituximab) combined with your chemotherapy. This is called ‘chemo-immunotherapy’.
• Some people have radiotherapy as well as chemotherapy.
• Some people need more intensive treatments, such as high-dose chemotherapy or a stem cell transplant.
• Targeted therapies are used to treat certain types of high-grade non-Hodgkin lymphoma.

The next section summarises the most common treatment options for high-grade non-Hodgkin lymphoma. Treatment for particular types of non-Hodgkin lymphoma is outlined on pages 133 to 151.
Early stage high-grade non-Hodgkin lymphoma

Some types of early stage (stage 1 or 2) high-grade non-Hodgkin lymphoma can be successfully treated with a shorter course of chemotherapy or chemo-immunotherapy (usually three to four cycles) followed by radiotherapy to the area affected by lymphoma.

Your medical team might recommend six cycles of chemotherapy or chemo-immunotherapy instead if:

• the type of lymphoma you have is not suitable for a shorter course chemotherapy
• your lymphoma is affecting extranodal sites
• you have very large lymph nodes (bulky disease)
• your lymphoma affects areas that are not suitable for radiotherapy.

Advanced stage high-grade non-Hodgkin lymphoma

For most types of advanced stage (stage 3 or 4) high-grade non-Hodgkin lymphoma, you are likely to have a longer course of chemotherapy or chemo-immunotherapy (usually six cycles).
Most people with advanced-stage high-grade non-Hodgkin lymphoma do not have radiotherapy. However, you might have radiotherapy after chemotherapy if you still have an active area of lymphoma or if you had very large lymph nodes (bulky disease). You might also have radiotherapy to relieve symptoms caused by large lumps of lymphoma pressing on nearby structures, or to reduce the risk of lymphoma coming back in vulnerable parts of your body.

**More intensive treatments**

Some types of high-grade non-Hodgkin lymphoma, such as primary central nervous system lymphoma and some types of peripheral T-cell lymphoma, have a higher risk of relapsing after initial treatment or might not respond well to standard chemotherapy.

These types of lymphoma might be treated with more intensive chemotherapy, if you are fit enough. 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.

For some types of high-grade non-Hodgkin lymphoma, if you respond well to your chemotherapy and you are well enough, your medical team might recommend a stem cell transplant (see page 73). A stem cell transplant could give you a better chance of staying in remission (no evidence of lymphoma) for longer.
CNS prophylaxis

Rarely, some types of high-grade non-Hodgkin lymphoma can spread to your brain or spinal cord (your central nervous system or CNS). If your medical team think you are at high risk of this, you have chemotherapy to help prevent it. This is called ‘CNS prophylaxis’. It involves having a chemotherapy drug that is able to cross from your bloodstream to your CNS. Treatment can be given into a vein (intravenous chemotherapy) or into your spinal fluid during a lumbar puncture (intrathecal chemotherapy; page 63).

Research and clinical trials

Your medical team might ask you if you would like to consider taking 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.

Some people considering taking part in a trial worry that they might get a ‘dummy’ treatment. You will always have active treatment in a trial if you would be having active treatment outside of a clinical trial.

“I feel fortunate to have taken part in the trial. It encouraged me to learn about my illness, however scared I was at first. The trial nurses were always there if I had any questions and I was monitored closely after finishing treatment.
Roger, diagnosed with primary CNS lymphoma, age 48

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

Go to lymphoma-action.org.uk/TrialsLink for more information about clinical trials, or to search for a trial that might be suitable for you. 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 generally more likely to experience serious side effects than younger people.

Your medical team always aim 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 have and might recommend a less intensive treatment if they think you have a higher risk of side effects.

For example, if you have heart or lung problems, there might be some chemotherapy drugs that are not 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 84). You might also be more sensitive to the side effects of radiotherapy.
If your medical team thinks you have a higher risk of side effects, they will adapt your treatment to suit your individual circumstances. Your medical team might:

- avoid using particular chemotherapy drugs that are more likely to cause side effects
- give you a lower dose of some drugs
- reduce how often you have your chemotherapy, giving your body longer to recover between each cycle
- monitor you more frequently
- add medicines that support your body to make treatment safer.

Ask your medical team what treatment they recommend and why they think it is the best option for you.
How is high-grade NHL treated?
I had R-CODOX/R-IVAC, which I was told was a more intense regimen because of the type and stage of my lymphoma. Having had a few weeks to slowly come to terms with having cancer, it was a shock to find out I would need to stay in hospital for around 3 months to have my chemo. I kept a list of every single dose I was going to receive and I ticked each one off, dose by dose.

Nicola, diagnosed with diffuse large B-cell lymphoma in 2017, age 44

Photo credit: Vicki Sharp Photography
Having treatment for high-grade non-Hodgkin lymphoma

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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 (page 82).

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.

Having chemotherapy

Most people have chemotherapy for high-grade non-Hodgkin lymphoma as an outpatient in a day case 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.

If you are having more intensive chemotherapy, you might have to stay in hospital for your treatment. Even if you are not having intensive therapy, you might need to stay in hospital for your first treatment to make sure you don’t develop any serious problems such as *tumour lysis syndrome* (page 98). You might also need to stay in hospital if you develop side effects such as an infection or very low blood counts (page 84).

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.

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.

• 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.

“I had a Hickman® line fitted, which was a great piece of equipment. It made everything so much easier.”

Jennie, diagnosed with Burkitt lymphoma, age 27
Having treatment for high-grade NHL
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 intravenous 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.

Having intrathecal chemotherapy

If you have lymphoma that has spread to your central nervous system (CNS), or your medical team think there is a high risk that it might spread to your CNS, you might also have **intrathecal** chemotherapy. This is chemotherapy that is injected into the fluid around your spinal cord through a **lumbar puncture** (see page 34).

Intrathecal chemotherapy can be used to give drugs that cross from your bloodstream into your brain and spinal cord in lower doses than you need if you have them intravenously.
Chemotherapy regimens for high-grade non-Hodgkin lymphoma

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

Your medical team should tell you about your treatment, including what you have and when. They should also be able to tell you what side effects to expect.

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.

I was told my lymphoma would be treated aggressively with full-time stays in hospital.
Kathleen, diagnosed with Burkitt lymphoma in 2006, age 60

For information about the side effects of lymphoma treatment and tips on how to cope with them, see pages 82 to 98.
Common regimens for high-grade non-Hodgkin lymphoma

The regimens listed in this section are often combined with rituximab. In this case, the name has an ‘R’ at the beginning (for example, R-CHOP).

The most common chemotherapy regimen for high-grade non-Hodgkin lymphoma is CHOP.

**CHOP** is cyclophosphamide, doxorubicin (or hydroxydaunorubicin), vincristine (also known as Oncovin®) and prednisolone.

A single **cycle** of 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. Depending on how much lymphoma you have in your body and how you respond to treatment, you usually have between three and six cycles of CHOP.

I had six cycles of R-CHOP and three doses of intrathecal methotrexate (CNS prophylaxis). The chemo days weren’t too bad, but I struggled with side effects (mainly fatigue and appetite loss) and a terrible headache after the first lumbar puncture.

Miriam, diagnosed with diffuse large B-cell lymphoma in 2018, age 56
More intensive regimens include:

- **DA-EPOCH**: dose-adjusted etoposide, prednisolone, vincristine (Oncovin®), cyclophosphamide and doxorubicin (or hydroxydaunorubicin)
- **CODOX-M**: cyclophosphamide, vincristine (Oncovin®), doxorubicin and methotrexate; this is sometimes alternated with IVAC
- **IVAC**: ifosfamide, etoposide (also known as VP-16) and cytarabine (also known as Ara-C)
- **MATRix**: methotrexate, cytarabine (also known as Ara-C), thiotepa and rituximab.

**Questions to ask about your chemotherapy regimen**

- What chemotherapy regimen do you recommend for me?
- How effective is it?
- How often will I have treatment?
- How long does each treatment session take?
- How many cycles will I have?

**Search ‘chemotherapy drugs’ at macmillan.org.uk to find out more about particular chemotherapy drugs or regimens.**
Antibody therapy such as rituximab

Antibody therapy is a type of targeted treatment. It aims to attack lymphoma cells more precisely than chemotherapy, causing fewer effects on healthy cells.

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
Rituximab

Rituximab is an antibody therapy that sticks to a protein called CD20 on the surface of B cells. T cells do not have CD20 on their surface, so rituximab is only used to treat B-cell lymphomas.

Having rituximab

Most people have rituximab combined with chemotherapy. You usually have it on the first day of each treatment cycle.

Before you have rituximab, you have medicines to help prevent any reactions to it. You then have rituximab through a drip into a vein (page 60). 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.

The most common reactions to rituximab treatment 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.

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

Brentuximab vedotin

Brentuximab vedotin is an antibody–drug conjugate: an antibody joined to a strong anti-cancer drug. The antibody targets a protein called CD30 on the surface of lymphoma cells, and carries the drug straight to them.

Brentuximab vedotin, combined with cyclophosphamide, doxorubicin and prednisone (known as CHP), is licensed to treat adults with anaplastic large cell lymphoma (ALCL) who have not been treated before.

Having brentuximab vedotin

You have brentuximab vedotin through a drip into a vein. It takes about 30 minutes. You usually have it once every 2 or 3 weeks.
Radiotherapy

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.

In high-grade non-Hodgkin, radiotherapy might be used to treat:

- localised (early stage) lymphoma – most often after a short course of chemotherapy or chemo-immunotherapy
- lymph nodes that were very large at the time of diagnosis – usually after a full course of chemotherapy or chemo-immunotherapy
- areas of lymphoma that are affecting critical parts of your body (for example, pressing on the spinal cord).
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 2 to 4 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.

For information about the side effects of lymphoma treatment, see pages 82 to 98, which include tips on how to cope with the side effects.
Stem cell transplant

If you have a type of lymphoma that has a high risk of coming back (relapsing) and you respond to initial chemotherapy, your doctor might recommend a **stem cell transplant**. This involves having high-dose chemotherapy.

High-dose chemotherapy can reduce the risk of your lymphoma **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 all the normal blood cells your body needs.

A stem cell transplant is a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells. This allows you to have high-dose chemotherapy.

Your medical team might recommend a stem cell transplant if you have:

- some types of T-cell lymphoma (page 140)
- primary CNS lymphoma (page 136).

They might also recommend a stem cell transplant if you have another type of high-grade non-Hodgkin lymphoma that has come back or not responded to initial treatment.
Usually, the 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.

**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 your 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. 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.
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.

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.
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 84) 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.

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.
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.

Other medicines to help with side effects

You also 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 or antibiotics.

Following my first chemotherapy session the doctors decided to administer a dose of steroids to help me. Because of my diagnosis, they felt it would be most effectively administered intrathecally. This meant a large needle being inserted into my spine, like a lumbar puncture, to inject the steroids. This was very uncomfortable and stressful but the effect made it all worthwhile. After hardly being able to stand up, I was doing a jig!

Richard, diagnosed with primary central nervous system lymphoma, age 53
Summary

• 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.
• Rituximab is an antibody therapy that is used to treat B-cell lymphomas. You usually have it in combination with chemotherapy.
• 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.
• You also have medicines to treat or prevent side effects or symptoms. This might include steroids, growth factors, anti-sickness drugs and antibiotics.
I coped well with the first few treatments, but as the sessions wore on, I became weaker and developed some side effects.

Bernard, diagnosed with diffuse large B-cell lymphoma, age 60
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 your medical team

- What side effects might I get? How long might these last?
- Are there any potential late effects (side effects that happen months or year after treatment finishes – see page 119)?
- 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 119). 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 treatments 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.

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 77) to help boost your neutrophil count.
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 help lower your risk of infection

• 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 or crowded shops.
• 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 litter trays and animal poo.
• Wear gloves for gardening.
• Visit your dentist before you start treatment for lymphoma – you might not be able to have any dental work done during or soon after treatment because of increased risk of infection.

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

For more information about risk of 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 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.

“My worst fear, sickness, never happened at all thanks to the antiemetic medicines.”
Martin, diagnosed with DLBCL in 2018, age 64

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 once you finish your 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.

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 and pulses, and 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.
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. They 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

Many chemotherapy drugs used to treat high-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 worried about hair loss.

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

• Pace yourself.
• 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, tingling and sometimes pain in your fingers and toes but 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 comfortable 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.
When cancer cells break down, they release chemicals into your bloodstream. Usually, your kidneys remove these chemicals. If cancer cells are broken down very rapidly, the chemicals might build up faster than your kidneys can remove them, leading to a chemical imbalance that can damage your kidneys or your heart. This is called **tumour lysis syndrome**. It affects up to 6 in every 100 people with high-grade cancers.

You are more likely to develop tumour lysis syndrome if you have a lot of cancer cells in your body (known as a ‘high tumour burden’) and they are dividing rapidly, because treatment can kill these cells very quickly. Symptoms of tumour lysis syndrome might include feeling or being sick, low appetite, weeing less than usual, muscle cramps and heart palpitations.

If you are at risk of tumour lysis syndrome, your medical team will monitor you very closely. You might have a drip (intravenous fluids) and medicines to help prevent it developing, or to treat it if it does develop.

If your medical team think you are at risk of developing tumour lysis syndrome, ask them what signs you should look out for.
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.

"At times I felt like I’d been taken away from everyone and everything I knew and loved. I couldn’t go to work, I couldn’t be a mum, I couldn’t even be at home, eat what I wanted or go outside for fresh air.

Nicola, diagnosed with diffuse large B-cell lymphoma in 2017, age 44"

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 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.

I tried to run throughout treatment on days I felt strong enough, but I often had to settle for long walks instead. Bernard, diagnosed with diffuse large B-cell lymphoma, age 60

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.

**Sex and contraception**

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 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 up to 2 years after finishing treatment before trying to start a family. There is more information on lymphoma treatment and fertility on page 121.

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

**Summary**

- No one can tell you exactly how treatment for high-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.
- Talk to your medical team about the support available to you.
- 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.
I know I’m not out of the woods yet. The greatest chance of recurrence is in the first 2 years and I’m still quite early in. Engaging with Lymphoma Action in various ways makes me feel as well informed as I need to be should I relapse.

Martin, diagnosed with DLBCL in 2018, age 64
What happens if high-grade non-Hodgkin lymphoma comes back or doesn’t respond to treatment?

What is relapsed or refractory lymphoma? 106

How is relapsed or refractory high-grade non-Hodgkin lymphoma treated? 107
What is relapsed or refractory lymphoma?

Most types of high-grade non-Hodgkin lymphoma respond well to treatment. However, in some people, the lymphoma does not respond (refractory lymphoma), gets worse (progressive lymphoma) or comes back after responding to treatment (relapsed lymphoma).

Some types of high-grade lymphoma, such as T-cell lymphomas, are more likely to relapse than others.

Lymphoma is most likely to come back within 2 years of the end of your first treatment. Generally, over time, lymphoma is less likely to come back. If you experience progressive disease or a relapse, the lymphoma might come back where it was before or it might affect another part of your body.

If I have aches, pains or unexplained lumps, I do not hesitate to see my doctor. No, I am not turning into a hypochondriac, but I am only too well aware that cancer generally needs to be identified quickly and I do not propose to take any chances.
Kathleen, diagnosed with Burkitt lymphoma in 2006, age 60
How is relapsed or refractory high-grade non-Hodgkin lymphoma treated?

If your lymphoma doesn’t respond to treatment, gets worse 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:

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

More chemo-immunotherapy

Many people with high-grade non-Hodgkin lymphoma that has come back or has not responded to treatment have more chemo-immunotherapy. If you are fit enough, this is likely to be more intensive than your first treatment. It is sometimes called ‘salvage therapy’ or ‘second-line therapy’. It aims to reduce your lymphoma as much as possible.

Lots of different regimens are used for salvage therapy. Your medical team should explain which one they think is best for you. You might also have radiotherapy if you have lymphoma that is causing local symptoms.
Chemotherapy regimens you might have include:

- **GDP**: gemcitabine, dexamethasone + cisplatin (Platinol®)
- **DHAP**: dexamethasone, high-dose cytarabine (Ara-C) + cisplatin (Platinol®)
- **ICE**: ifosfamide, carboplatin + etoposide
- **IVE**: ifosfamide, etoposide (VP-16) + epirubicin
- **ESHAP**: etoposide, methylprednisolone (Solu-Medrone®), high-dose cytarabine (Ara-C) + cisplatin (Platinol®)
- **Gem-P**: gemcitabine, cisplatin + methylprednisolone
- **BR**: bendamustine + rituximab.

These regimens are often combined with rituximab (R).

**Stem cell transplant**

If salvage chemotherapy is effective against your lymphoma and you are well enough, your doctor is likely to suggest that you have a stem cell transplant (page 73) to increase your chance of having a longer-lasting remission. A stem cell transplant works best if your lymphoma goes back into remission (ideally complete remission) following salvage therapy.
Targeted drugs

Targeted drugs are available to treat some types of relapsed or refractory lymphoma.

Visit lymphoma-action.org.uk/TargetedDrugs for the latest information on targeted drugs for high-grade non-Hodgkin lymphoma.

Brentuximab vedotin

If you have relapsed or refractory anaplastic large cell lymphoma (ALCL), you might have treatment with a targeted drug called brentuximab vedotin (page 69). You have it through a drip into a vein. It takes about 30 minutes. You usually have it once every 2 or 3 weeks.

Polatuzumab vedotin

Polatuzumab vedotin is an antibody–drug conjugate that sticks to a protein called CD79b on the surface of some lymphoma cells. It carries an anti-cancer drug straight to the cells.

At the time of writing, the National Institute for Health and Care Excellence (NICE) is deciding whether polatuzumab vedotin should be available on the NHS for people with relapsed or refractory DLBCL who aren’t able to have a stem cell transplant.
You have polatuzumab vedotin combined with rituximab and a chemotherapy drug called bendamustine. You usually have it on the first day of each 21-day treatment cycle.

First you have medicines to help prevent any reactions to the drug. Then you have polatuzumab vedotin through a drip into a vein. It takes about 90 minutes.

**CAR T-cell therapy**

CAR T-cell therapy involves collecting your own T cells and genetically modifying (changing) them so they can recognise and kill lymphoma cells.

You might have CAR T-cell therapy if you have diffuse large B-cell lymphoma (DLBCL), primary mediastinal large B-cell lymphoma (PMBL) or transformed low-grade lymphoma that has come back or not responded after at least two previous courses of treatment. CAR T-cell therapy is a very intensive treatment that can cause serious side effects. You have to be fit enough to have it.

CAR T-cell treatments have to be made individually for each person. This can take several weeks. You are likely to have other treatments to keep your lymphoma under control while the CAR T cells are being made. This is called ‘bridging therapy’.
1. You have T cells collected from your blood.
2. Your T cells are sent to a lab where the CAR T cells are made. During this time, you might have bridging therapy to keep your lymphoma under control.
3. You have low-dose chemotherapy (called ‘lymphodepleting chemotherapy’) to reduce the number of white blood cells in your body to make room for the CAR T cells.
4. You have the CAR T cells through a drip into a vein.
CAR T-cell therapy can cause serious side effects. It is only available in selected hospitals with the facilities and staff to treat these side effects effectively. You have to stay in hospital to have the treatment, and you need to stay close to the hospital for at least a month afterwards in case you develop side effects.

Although CAR T-cell therapy is a major treatment advance, for some people it is not effective and their lymphoma does not respond or returns after treatment.

Visit lymphoma-action.org.uk/CARTcells or phone 0808 808 5555 to learn more.

Clinical trials

New treatments for non-Hodgkin lymphoma are often tested first in clinical trials in people with relapsed or refractory disease. You might be able to access new, experimental treatment by taking part in a clinical trial.

If you do consider entering a clinical trial, your medical team will talk to you about this in detail.

Visit lymphoma-action.org.uk/TrialsLink for information about clinical trials, or to search for a trial that might be suitable for you. We also produce a book about clinical trials. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.
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.
- If you have relapsed or refractory high-grade non-Hodgkin lymphoma, you are likely to have treatment with a more intensive chemo-immunotherapy regimen. This is sometimes called ‘salvage therapy’.
- If you respond to salvage therapy and you are fit enough, you might have a stem cell transplant.
- Some people might have treatment with targeted drugs or CAR T-cell therapy.
- Your doctor might ask you if you’d like to take part in a clinical trial.
Recovering from cancer, I expected things to go smoothly, but soon realised that I would have to come to terms with setbacks, such as infections and fatigue. I have now come to accept that things will not always go to plan and that’s just life. But I am proactive and try and think about how I, or someone else, can help. I call this setback management.

Richard, diagnosed with primary CNS lymphoma, age 53
What happens after treatment?

How you might feel after treatment 116
Follow-up 117
Late effects of treatment 119
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 making 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 157).

It’s much more scary once treatment’s finished. Until then you’re caught up in frequent hospital appointments and treatments. Suddenly it feels like you’re cut loose. That said, the haematology nurses are still at the end of a phone if needed.

Miriam, diagnosed with DLBCL in 2018, age 56
Follow-up

When you finish treatment, you have an appointment with your medical team to talk about your physical, emotional, and social needs. This allows your team to create a care and support plan that’s specific to you.

You are likely to have a follow-up appointment every 2 to 3 months at first. After a while, your appointments might become less frequent. Some hospitals have a self-management system, which means that instead of having pre-booked appointments, you can arrange your own appointments as-and-when you feel you need one.

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 119).

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 can contact your hospital team at any time. Don’t wait until your next appointment if you are worried.
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.

Most hospitals offer follow-up appointments for at least 2 years after you finish treatment. This is an important time in terms of your recovery from treatment and the risk of relapse. Some hospitals offer follow-up for 5 years or longer.

After your follow-up period ends, your GP usually becomes your main point of contact. They 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 have had treatment for lymphoma.

*Local health and wellbeing events have been marvellous in finding out about services available – from therapies to support groups.*

Ros, diagnosed with diffuse large B-cell lymphoma, age 56
Late effects of treatment

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

The risk of developing late effects might seem worrying, but knowing what conditions you might be at risk of can give 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 your medical team

- 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 65).

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 your treatment but they can develop sooner. Symptoms might 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 high-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.**

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.

**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

• Find out what late effects you are at risk of and know what symptoms to look out for.
• If you are a smoker, try to give up.
• 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 common to experience mixed feelings when you finish treatment.
• You have regular 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.
Lymphoma – especially a rarer type – feels like a very isolating disease and I had not come across anyone with the same type as mine. I was so ill with the treatment. My Lymphoma Action buddy saved my life. She told me that it would not always be like this. She said that at some point I would look back and say ‘I don’t know how I got through this, but I did’. And she knew, because she’d got through it.

Tracey, diagnosed with primary mediastinal B-cell lymphoma, age 42
Living with and beyond lymphoma

Your feelings 126
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When someone close to you has lymphoma 130
Your feelings

No one can tell exactly how you will feel when you are diagnosed with high-grade non-Hodgkin lymphoma, 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 157) offer emotional support if you, or any of your family or friends, want to talk to someone about your lymphoma.
Depression

There might be times when you don’t want to talk to anyone and just want to be alone. It’s 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 GP is a good first contact. There is a lot of support, treatment and counselling available for people with depression.

- 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 to seek support.
- Search ‘IAPT’ at nhs.uk to refer yourself for free psychological therapies on the NHS.
- 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 had a lot of psychological counselling. Before cancer, I would have been quite dismissive of this type of support, but I found it enormously helpful.”
Ian, diagnosed with Burkitt lymphoma, age 47

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
Making informed choices

You might find it useful to learn more about your type of lymphoma and the treatment you’ve had. This could help you:

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

“I found writing a blog really therapeutic. It was a way of getting a lot of anger and fear off my chest. Writing the blog helped me get through the whole process and maintain a level of sanity.”
Kat, diagnosed with double-hit lymphoma, age 32
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. You might not know how best to support them – but there are lots of things you can do.

“
My husband visited every single morning once he’d taken our little girl to school, so it felt like a little bit of the real me was coming in to see me every day. I don’t know how he did it but he put on his cheeky chappy act and brought light to the whole ward, every single day. Nicola, diagnosed with diffuse large B-cell lymphoma in 2017, age 44

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.
One important message I have is the need to care for carers. Family and friends have to master their own fears. Cancer impacts upon whole families, friends and communities.
Kathleen, diagnosed with Burkitt lymphoma in 2006, age 60

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 might 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. Carers UK (carersuk.org) and Carers Trust (carers.org) are helpful sources of support.
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.
Types of high-grade non-Hodgkin lymphoma

High-grade B-cell lymphomas 134
- Diffuse large B-cell lymphoma (DLBCL) 135
- Rarer types of large B-cell lymphoma 136
- Burkitt lymphoma 140

High-grade T-cell lymphomas 141

Lymphoblastic lymphoma 149

High-grade non-Hodgkin lymphomas associated with immunodeficiency 150
High-grade B-cell lymphomas

Most cases of high-grade non-Hodgkin lymphoma develop from B-cell lymphomas. There are many different types of B-cell lymphoma.

It is important for doctors to find out what type of B-cell 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 high-grade B-cell 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 high-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.
**Diffuse large B-cell lymphoma (DLBCL)**

DLBCL is the most common type of high-grade non-Hodgkin lymphoma. It typically affects people over 65, but it can develop at any age. It is slightly more common in men than women.

**Symptoms:** Most people have swollen lymph nodes that grow quickly. These can be deep inside the body where you might not feel them. You might have other symptoms depending on where your lymphoma starts.

**Treatment:** Most people have chemo-immunotherapy (page 107). The most commonly used regimen is R-CHOP. You might also have radiotherapy, particularly if you have large lumps of lymphoma.

If you are at high risk of your lymphoma coming back, your medical team might recommend a more intensive chemo-immunotherapy regimen.

If you have a high risk of your lymphoma spreading to your **central nervous system**, you might also have **CNS prophylaxis** (page 51) to help prevent this.

If you have DLBCL that doesn’t respond or comes back after treatment, you are likely to have more treatment, such as more chemo-immunotherapy, a stem cell transplant, targeted drugs or CAR T-cell therapy (pages 110–112).
Rarer types of large B-cell lymphoma

There are several rare types of large B-cell lymphoma that can behave differently to DLBCL. They sometimes need more intensive treatment.

Primary central nervous system lymphoma

Primary central nervous system (CNS) lymphoma is lymphoma that develops in the brain, eyes, or, rarely, the spinal cord. It is usually a type of DLBCL.

Symptoms might include changes in personality, behaviour or vision; limb weakness; memory or balance problems; confusion; seizures; or headaches.

CNS lymphoma needs prompt treatment. After the diagnosis is confirmed by biopsy, you usually have steroids first to improve your symptoms. Most people then have intensive chemotherapy that includes methotrexate (which is able to cross from the bloodstream to the brain) and rituximab. If you are fit enough, you might have a chemotherapy regimen called MATRix. After chemotherapy, you might have a stem cell transplant, or radiotherapy to your brain.
Primary mediastinal large B-cell lymphoma (PMBL)

PMBL develops in the **thymus** and can cause a large swelling inside your chest. It usually affects people in their 20s and 30s, more commonly women. You might have R-CHOP followed by radiotherapy, or you might have a more intensive chemo-immunotherapy regimen. You might be offered treatment as part of a clinical trial (page 112).

**ALK-positive large B-cell lymphoma**

This is a very rare type of lymphoma where the lymphoma cells make a protein called anaplastic large-cell kinase (ALK). It usually causes swollen lymph nodes but it can develop in your chest or other places.

Unlike DLBCL, the lymphoma cells don’t usually make the CD20 protein. You have similar treatment to DLBCL (page 135) but without rituximab (which targets CD20).

**EBV-positive DLBCL, not otherwise specified**

This subtype of DLBCL is linked to a virus called Epstein–Barr virus (EBV). It typically develops in people over 50. Symptoms depend on where the lymphoma is growing. Treatment is usually the same as for DLBCL (page 135).
T-cell/histiocyte-rich large B-cell lymphoma

This type of lymphoma mainly affects middle-aged men. It usually causes swollen lymph nodes, swelling of the liver or spleen, and B symptoms. It can sometimes look like a type of Hodgkin lymphoma under a microscope so it is important it is diagnosed correctly. Most people are treated with R-CHOP (page 65).

Intravascular large B-cell lymphoma

This very rare type of lymphoma develops in small blood vessels. It most often affects people in their 60s. Symptoms depend on where it develops but can include nervous system symptoms, such as confusion, seizures, dizziness or weakness; skin lumps or patches; a swollen liver or spleen; and B symptoms. Treatment is usually the same as for DLBCL (page 135) but often also includes treatment directed at the central nervous system, such as high-dose methotrexate.
Double-hit and triple-hit lymphoma

These are types of lymphoma where the lymphoma cells have two (double-hit) or three (triple-hit) major lymphoma-related changes in their genes. They can be more difficult to treat than typical DLBCL. You might have intensive chemo-immunotherapy or be offered treatment as part of a clinical trial (page 112). You might also have treatment to prevent the lymphoma spreading to your central nervous system (page 51).

Grey zone lymphomas

Grey zone lymphomas have features of more than one type of lymphoma, usually PMBL and Hodgkin lymphoma. They usually affect people aged 20 to 40. Most people with grey zone lymphoma develop very enlarged lymph nodes in their chest.

There is no standard treatment for grey zone lymphomas. Your doctor chooses a regimen based on your individual circumstances. You are likely to be offered chemo-immunotherapy or to have treatment as part of a clinical trial (page 112). You might also have radiotherapy if you have large lumps of lymphoma (‘bulky’ disease).
Burkitt lymphoma

Burkitt lymphoma is a very fast-growing type of B-cell lymphoma. It usually affects children and young adults.

**Symptoms:** Symptoms usually develop quickly. Most people develop lots of swollen lymph nodes in different parts of the body, often including the tummy (abdomen) and bowel. You might get an enlarged spleen and liver. The lymphoma can spread to your bone marrow and central nervous system (CNS).

**Treatment:** Burkitt lymphoma develops quickly and needs intensive treatment, which is usually successful.

Most people have intensive chemo-immunotherapy regimens, such as R-CODOX-M/R-IVAC. You might be offered a less intensive regimen, such as DA-EPOCH-R. Treatment usually includes drugs that reach your CNS and might involve intrathecal chemotherapy (page 63).

A large number of lymphoma cells can be killed very quickly during treatment for Burkitt lymphoma. This can cause tumour lysis syndrome (page 98).
High-grade T-cell lymphomas

T-cell lymphomas are rare. There are lots of different types of T-cell lymphoma with complicated names based on the type of cell they develop from or the proteins they make.

It is important to find out what type of T-cell 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 high-grade T-cell 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 many of the different types of high-grade T-cell non-Hodgkin lymphoma. View or download our information sheets at lymphoma-action.org.uk/Tcell or call 0808 808 5555 to request a copy.
Peripheral T-cell lymphoma not otherwise specified (PTCL-NOS)

PTCL-NOS includes all high-grade T-cell lymphomas that don’t fit into another category. These can develop at any age, but they are more common in people in their 60s. They affect more men than women.

**Symptoms:** People with PTCL-NOS might have enlarged lymph nodes but symptoms are often due to lymphoma growing outside the lymph nodes. PTCL-NOS can grow in the bone marrow, the liver or spleen, the chest or the skin. **B symptoms** are common.

**Treatment:** There is no standard treatment for PTCL-NOS. Your doctor chooses a regimen based on your individual circumstances. You are most likely to be offered treatment as part of a clinical trial or to have a chemotherapy regimen such as CHOP (page 65). If you respond to treatment and you are fit enough, your medical team might recommend a stem cell transplant (page 73) to make your remission last longer.
**Anaplastic large cell lymphoma (ALCL)**

ALCL is divided into ALK-positive ALCL and ALK-negative ALCL depending on whether the lymphoma cells make a protein called anaplastic large-cell kinase (ALK). ALCL can also develop in the skin or, rarely, in people who have had breast implants, but these types are typically slow-growing (low-grade).

ALK-positive ALCL is more common in children and younger adults. ALK-negative ALCL tends to affect people over 40. Both types are more common in men.

**Symptoms:** Most people with ALCL have enlarged lymph nodes and B symptoms. ALCL often affects extranodal sites, like the skin, lungs, liver, bone and bone marrow.

**Treatment:** There is no standard treatment for ALCL. Your doctor chooses a regimen based on your individual circumstances. You might be offered brentuximab vedotin + CHP (page 65) or a chemotherapy regimen such as CHOP (page 65) or CHEOP (CHOP + etoposide). People with early stage ALCL might also have radiotherapy (page 70).

If you have ALK-negative ALCL and you respond to chemotherapy, you might have a stem cell transplant (page 73) to make your remission last longer. ALK-positive ALCL is less likely to relapse.
Angioimmunoblastic T-cell lymphoma (AITL)/follicular T-cell lymphoma (FTCL)

AITL and FTCL develop from a type of white blood cell called a ‘follicular helper T cell’ (T\textsubscript{FH}). Some people also have abnormal B cells. These types of lymphoma typically affect people in their 60s and 70s.

**Symptoms:** AITL and FTCL are often fast-growing. People typically have enlarged lymph nodes in several places, B symptoms, a skin rash and anaemia. You might get more infections than usual. If your lymphoma cells make abnormal antibodies, you might have immune reactions, such as low blood counts or swollen joints, caused by the antibodies attacking healthy cells.

Most people with AITL are diagnosed at an advanced stage, but people with FTCL are more likely to be diagnosed at an earlier stage.

**Treatment:** AITL and FTCL are usually treated in the same way. You might be offered treatment as part of a clinical trial, or have a chemotherapy regimen such as CHOP (page 65). Occasionally, you might also have rituximab, if you have high levels of a virus called EBV in your blood due to a high number of abnormal B cells.

If you respond to treatment and you are fit enough, your medical team might recommend a stem cell transplant (page 73) to make your remission last longer.
Intestinal T-cell lymphomas

Intestinal T-cell lymphomas are rare. They develop in your small bowel (gut or intestine). There are two types:

- Enteropathy-associated T-cell lymphoma (EATL) only develops in people who have coeliac disease (an autoimmune condition affecting the small bowel).
- Monomorphic epitheliotropic intestinal T-cell lymphoma (MEITL) is not linked to coeliac disease.

**Symptoms:** Intestinal T-cell lymphomas cause bowel and stomach symptoms, such as tummy pain, weight loss and diarrhoea. You might be exhausted and malnourished if you can’t absorb food properly. People with intestinal T-cell lymphomas are often very unwell and malnourished by the time they are diagnosed.

**Treatment:** Intestinal T-cell lymphomas can be difficult to treat. You might be offered treatment as part of a clinical trial (page 112). Otherwise, you might have chemotherapy (with an intensive regimen if you are fit enough), followed by a stem cell transplant (page 73). Some people need bowel surgery first (for example, if the lymphoma has blocked your bowel).

Visit coeliac.org.uk for more information on coeliac disease.
Adult T-cell leukaemia/lymphoma (ATL)

ATL is a type of lymphoma that only affects people with human T-lymphotropic virus type 1 (HTLV-1). HTLV-1 infection is rare in the UK. ATL develops in about 1 in 20 people with HTLV-1, usually many years after they got the infection.

There are two fast-growing types of ATL: lymphoma-type ATL and acute ATL. There are also slower-growing types but we do not cover them here.

**Symptoms:** You might have enlarged lymph nodes, B symptoms, a swollen liver and spleen, skin rash, and high levels of calcium in your blood.

**Treatment:** If you are fit enough, you are likely to have an intensive chemotherapy regimen (page 50). If not, you might have lower doses of chemotherapy or less intensive options such as oral chemotherapy. You also have antiviral drugs to control your HTLV-1 infection.

If you have a high risk of your lymphoma spreading to your central nervous system, you might also have CNS prophylaxis (page 51) to help prevent this.

If you respond to treatment and you are well enough, you might have a donor (allogeneic) stem cell transplant (page 73) to make your remission last longer.
Hepatosplenic T-cell lymphoma

This is a rare type of T-cell lymphoma that develops in the liver and spleen. It usually affects younger adults, typically people in their mid-30s. It is more common in people with immune system problems.

**Symptoms:** The most common symptoms are a swollen liver and spleen, low blood counts and *B symptoms*.

**Treatment:** There is no standard treatment for hepatosplenic T-cell lymphoma. Your doctor chooses a regimen based on your individual circumstances. You are most likely to be offered treatment as part of a clinical trial or to have chemotherapy (page 65). This is often a more intensive regimen. If you respond to treatment and you are fit enough, your medical team are likely to recommend a donor (allogeneic) stem cell transplant (page 73) to make your remission last longer.
Extranodal NK/T-cell lymphoma, nasal type

Extranodal NK/T-cell lymphoma, nasal type (ENKTL) develops outside the lymph nodes (extranodal), most often in the nose. It can develop from T cells or another type of lymphocyte called ‘natural killer (NK)’ cells.

ENKTL is extremely rare in the UK. It tends to affect people in their 50s and 60s. It is strongly linked to infection with Epstein–Barr virus (EBV), but most people with EBV do not develop lymphoma.

**Symptoms:** Most people have a fast-growing lump inside the nose or in the sinuses (air-filled spaces) around the nose. The most common symptoms are a blocked nose, nosebleeds, weepy eyes or facial swelling. It is also common to have **B symptoms**, swollen lymph nodes, fatigue, and involvement of extranodal sites (for example, the skin, liver or bone).

**Treatment:** ENKTL can be difficult to treat. You might be offered treatment as part of a clinical trial (page 112), if a suitable one is available. Most people have chemotherapy regimens that include a drug called L-asparaginase. If you have localised lymphoma, you might also have radiotherapy (page 70) to the affected area.

If you respond to treatment and you are fit enough, your medical team are likely to recommend a stem cell transplant (page 73) to make your remission last longer.
Lymphoblastic lymphoma

Lymphoblastic lymphoma is rare. It develops from immature lymphocytes, usually T cells but occasionally B cells. It tends to affect children and young adults.

**Symptoms:** Most people have swollen lymph nodes inside the chest. This can cause a cough, shortness of breath, or a swollen neck or face. Some people have B symptoms or lymphoma in other parts of their body.

**Treatment:** Most people have intensive chemotherapy in three phases:

- Remission induction aims to get rid of as much lymphoma as possible. It includes intrathecal chemotherapy (see page 63). You usually stay in hospital to have it.
- Consolidation chemotherapy aims to destroy any lymphoma cells left behind. Some people might have a stem cell transplant (page 73) instead.
- Maintenance chemotherapy is given for around 2 years to prevent the lymphoma from relapsing. You might have it as tablets at home.

Lymphoblastic lymphoma is very similar to acute lymphoblastic leukaemia. For more detail, visit leukaemiacare.org.uk/acute-lymphoblastic-leukaemia
High-grade non-Hodgkin lymphomas associated with immunodeficiency

These are types of lymphoma that can develop in people with a low immune system (immunodeficiency).

Post-transplant lymphoproliferative disorder (PTLD)

PTLD refers to types of lymphoma that can develop in people who are taking drugs that dampen down the immune system (immunosuppressants) after an organ transplant or donor (allogeneic) stem cell transplant. PTLD is rare. Most people who have transplants do not develop it. Some types of PTLD are fast-growing.

Symptoms: Most people have swollen lymph nodes in the neck, armpit or groin, but PTLD can develop in other places. You might get B symptoms, which can be mistaken for signs of transplant rejection.

Treatment: Your lymphoma team works with your transplant team to make sure you get the most appropriate treatment. If possible, your dose of immunosuppressants is reduced. For early PTLD, this might be the only treatment you need. Most people are likely to have other treatment, too – usually rituximab (page 68), either on its own or with chemotherapy.
HIV-related lymphoma

People with HIV infection are more likely to develop lymphoma than people without HIV infection. The most common types of lymphoma in people with HIV are Burkitt lymphoma (page 140), DLBCL (page 135), primary CNS lymphoma (page 136) and Hodgkin lymphoma. Some very rare types of non-Hodgkin lymphoma are strongly linked with HIV infection. These are:

- primary effusion lymphoma (PEL), which grows in the cavities in your body (for example, around your lungs or in your tummy)
- plasmablastic lymphoma (PBL), which usually grows in your mouth or throat.

**Symptoms:** Most people have swollen lymph nodes. Many people with HIV develop lymphoma in their tummy or bowel, which might cause pain, swelling, sickness or diarrhoea. **B symptoms** are common.

**Treatment:** Your lymphoma team works with your HIV team to make sure you get the most appropriate treatment for both conditions. You are likely to have the standard treatment for the type of lymphoma you have. PEL is often treated with CHOP. PBL is generally treated with intensive chemotherapy, possibly followed by a stem cell transplant (page 73). You also have anti-retroviral therapy (ART) to treat your HIV.
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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 or email information@lymphoma-action.org.uk

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:
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:

- *Living with lymphoma*
- *Autologous stem cell transplant: a transplant using your own stem cells*

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 619409 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

**CLIC Sargent: Young Lives vs Cancer** provides emotional and practical support for young people with cancer and their families.
0300 330 0803 www.clicsargent.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

Teenage Cancer Trust provides cancer services and support for young people affected by cancer.
hello@teenagecancertrust.org  www.teenagecancertrust.org

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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This book is about high-grade non-Hodgkin lymphoma. It describes how high-grade non-Hodgkin lymphoma typically affects people, how it is treated and what to expect during and after treatment.

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)