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Lymphoma action

Jascap
FIGHTING CANCER – LIVING WITH IT

Non-Hodgkin Lymphoma

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Types of low-grade NHL

- Low-grade non-Hodgkin lymphoma*
- *Follicular lymphoma*
- *Mantle cell lymphoma*
- *Marginal zone lymphomas*
- *Waldenström's macroglobulinaemia (lymphoplasmacytic lymphoma)*

Types of high-grade NHL

- High-grade B-cell lymphomas*
- *Diffuse large B-cell lymphoma (DLBCL)*
- *Rarer types of large B-cell lymphoma*
- *Burkitt lymphoma*
- High-grade T-cell lymphomas*
- *Peripheral T-cell lymphoma not otherwise specified (PTCL-NOS)*
- *Anaplastic large cell lymphoma (ALCL)*
- *Angioimmunoblastic T-cell lymphoma (AITL)/ follicular T-cell lymphoma (FTCL)*
- *Intestinal T-cell lymphomas*
- *Adult T-cell leukaemia/lymphoma (ATL)*
- *Hepatosplenic T-cell lymphoma*
- *Extranodal NK/T-cell lymphoma, nasal type*
- *Lymphoblastic lymphoma*
- High-grade non-Hodgkin lymphomas associated with immunodeficiency*
- *Post-transplant lymphoproliferative disorder (PTLD)*
- *HIV-related lymphoma*

** Detailed factsheets on each of these types of NHL are available with JASCAP*

Glossary

About this book

Non-Hodgkin lymphoma is a type of blood cancer that develops from white blood cells called lymphocytes. It is a broad term that includes lots of different types of lymphoma.

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

Introduction to lymphoma

What is lymphoma?

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

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

Lymphoma is 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.

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

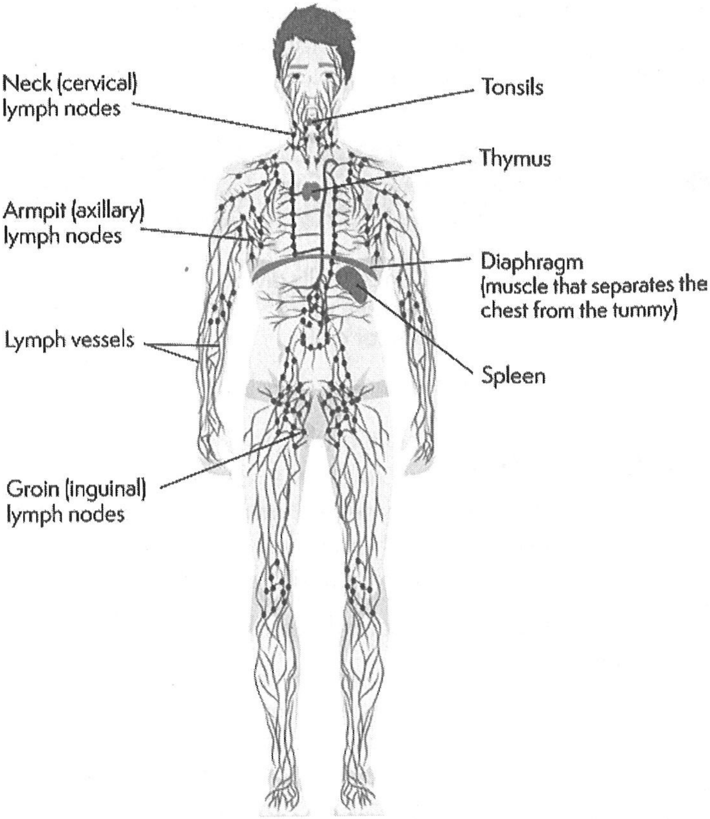


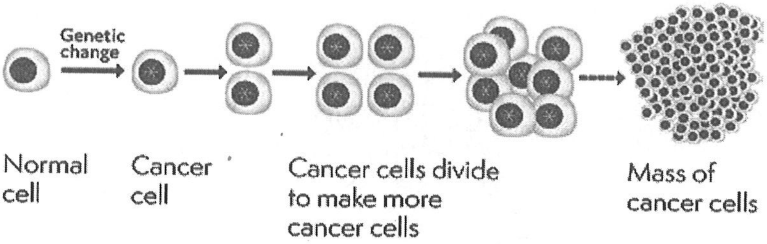
Figure: The lymphatic system

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.



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.

Low-grade and high-grade non-Hodgkin lymphoma

What is low-grade and 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). They work in different ways to protect your body from infection and illness.

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

  Either of these types of lymphocyte can grow out of control and cause lymphoma to develop.
- Non-Hodgkin lymphomas that develop from B cells are called B-cell lymphomas. Most lymphomas are B-cell lymphomas.
- Non-Hodgkin lymphomas that develop from T cells are called T-cell lymphomas. They are usually high-grade lymphomas.

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

There is more information on the different types of low-grade non-Hodgkin lymphoma.

Ask your medical team if you're not sure what type of lymphoma you have.

Who gets non-Hodgkin lymphoma?

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

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

What causes non-Hodgkin lymphoma?

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

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

Unlike many other types of cancer, lifestyle factors don't have much impact on your risk of developing lymphoma. Anyone can develop lymphoma but your risk is higher if you have problems with your immune system. For example, people who have HIV infection are more likely to develop lymphoma than other people. 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).

What are the symptoms of non-Hodgkin lymphoma?

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

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

Swollen lymph nodes

The most common symptom of 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 low-grade non-Hodgkin lymphoma have symptoms known as 'B symptoms'. These are one or more of the following:

- **Fever:** a high temperature (above 38°C) that might come and go.
- **Drenching sweats:** especially at night.
- **Unexplained weight loss:** losing weight quickly without trying to.

Other symptoms

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.

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 non-Hodgkin lymphoma?

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

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

Low-grade non-Hodgkin lymphoma can often be controlled for many years but it usually comes back (relapses) or gets worse (progresses) at some point. This might not be for many months or years.

Although a relapse can be very distressing, many people are treated successfully again. Most people with low-grade non-Hodgkin lymphoma have several different treatments over the course of their illness. It helps some people to think of it as a long-term (chronic) disease that needs treatment from time-to-time.

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 later pages 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
- the exact type of lymphoma you have
- how much lymphoma you have in your body and where it is (the stage of your lymphoma)
- 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.

Tests, scans and staging

How is 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 for lymphoma, but you might not need all of them.

Lymph node biopsy

A biopsy is the only way to tell for certain whether or not a lump is lymphoma. This means taking a sample from the lump (often a swollen lymph node) to be examined in a lab.

Sometimes the whole lymph node is removed (an 'excision' biopsy) and sometimes just a core of tissue is removed. The exact procedure depends on where the lump is. It usually involves having a minor operation performed by a surgeon or a radiologist under a local anaesthetic. Most people go home the same day.

Arrange for somebody to drive you home after your biopsy.

Your biopsy sample is sent to a laboratory to be examined under a microscope and to have specialised tests to find out what type of lymphoma you have. This is done by a pathologist. Biopsy 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.

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.

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

PET scans

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

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

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

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

Ultrasound scans

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

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 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.

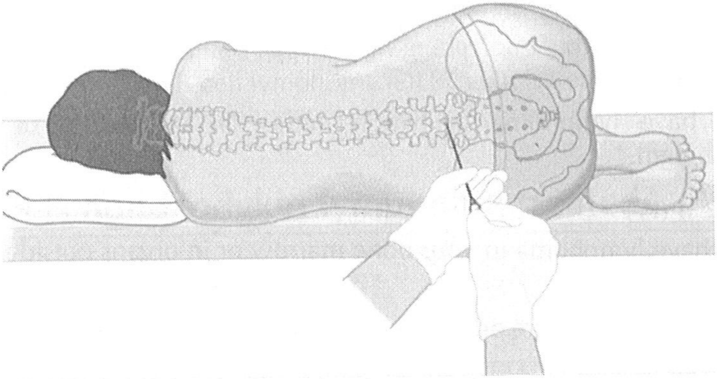
If you are very anxious, you might be able to have a sedative (a drug to help you relax).

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.



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.

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.

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.

A	You don't have any B symptoms.
B	You have one or more B symptoms (weight loss, night sweats or fevers).
E	You have lymphoma that started outside the lymphatic system ('extranodal' lymphoma). Extranodal lymphoma doesn't include lymphoma that started in a lymph node and spread to a body organ.
X	At least one of your affected lymph nodes is very large or 'bulky'.

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.

Grading of follicular lymphoma

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

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

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

How is non-Hodgkin lymphoma treated?

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.

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.

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

How does my medical team decide what treatment I need?

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

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

If you don't have symptoms, your medical team might not recommend treatment straightaway. Instead, you might be closely monitored (active monitoring or 'watch and wait').Your team should also talk to you about your physical, emotional and social needs. This is called a 'holistic needs assessment' or HNA.

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.

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.

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.

Treatment options for low-grade non-Hodgkin lymphoma

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

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

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

Early stage low-grade non-Hodgkin lymphoma

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

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

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

Advanced stage low-grade non-Hodgkin lymphoma

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

Most people with advanced stage low-grade non-Hodgkin lymphoma live for many years with their lymphoma, needing treatment from time-to-time.

If you have advanced stage follicular lymphoma that is not causing troublesome symptoms, you might have:

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

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

If your lymphoma is causing problems, your medical team are likely to recommend a course of chemotherapy combined with antibody therapy. This is known as 'chemo immunotherapy'. People with some types of low-grade lymphoma have a course of maintenance therapy after their initial treatment ends. This aims to keep the lymphoma under control for as long as possible.

More intensive treatments

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

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

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.

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. 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).

Research and clinical trials

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

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

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

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

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. 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.

Having treatment for low-grade and high-grade NHL

Active monitoring ('watch and wait')

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

It means that, while you are well, you can avoid the side effects of treatment for as long as possible. Treatment is still available when you need it, but this might not be for months or years. You might never need treatment.

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

You might have active monitoring when you are first diagnosed with lymphoma, or after a course of treatment that has shrunk your lymphoma but has not got rid of it completely.

Your medical team might suggest active monitoring if:

- your lymphoma is not causing troublesome symptoms
- your lymphoma is not growing quickly
- your blood tests don't show any significant problems

- your lymphoma is not affecting any of your major organs (such as your heart, lungs or kidneys).

Being on active monitoring

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

Starting treatment

Low-grade non-Hodgkin lymphoma grows slowly. It rarely needs urgent treatment.

You might end active monitoring and start treatment if:

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

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

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.

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.

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

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. You might also need to stay in hospital if you develop side effects such as an infection or very low blood counts.

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.

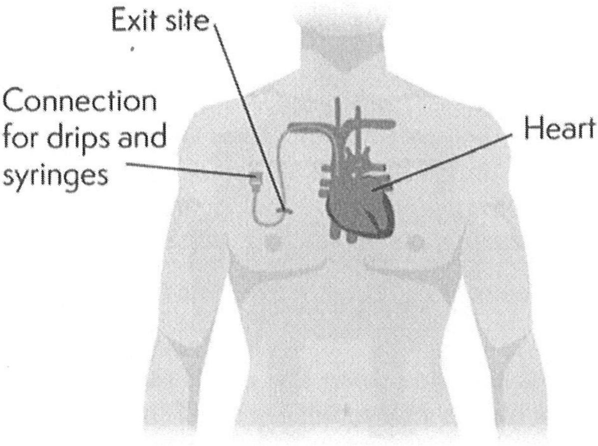
Having intravenous chemotherapy

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

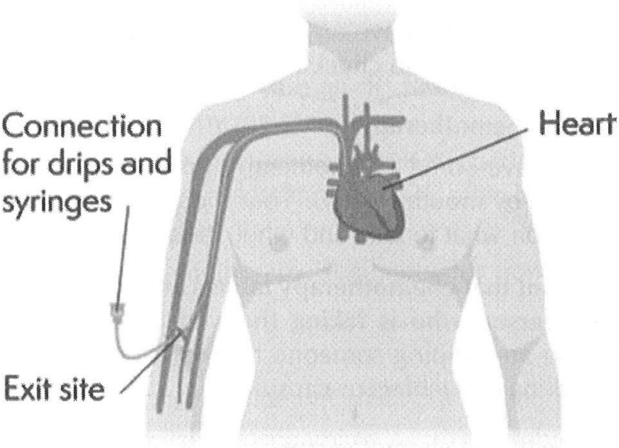
- A 'cannula' – a small, soft plastic tube that usually goes into a vein in the back of your hand. You have a new one put in each time you go for treatment. This is the most common way to have treatment for low-grade non-Hodgkin lymphoma.
- A 'central venous catheter', 'central line' or 'PICC line' – a longer plastic tube that goes into a vein in your arm or under the skin of your chest and ends in a larger vein near your heart. Examples include a Hickman® line and a Groshong® line. A central line usually stays in for all of your treatment. You might have one fitted if you need an intensive chemotherapy regimen. You go to

a day ward to have your line cleaned regularly, or a nurse might show you how to look after it at home.

- A 'port-a-cath' – a type of central line that ends in a port or chamber just under the skin on your chest. Your treatment can be injected into the port using a special needle.



A Hickman® central line



A PICC line

Your nurse can inject some chemotherapy drugs straight into your cannula or central line over a minute or two. Other chemotherapy drugs have to be given more slowly through a drip (infusion). This could take anywhere from 30 minutes to a number of hours, depending on the drugs you are having.

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.

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.

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 low-grade non-Hodgkin lymphoma

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

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

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

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

Common regimens for low-grade non-Hodgkin lymphoma

The regimens listed in this section are usually combined with antibody therapy, either:

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

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

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

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

Other chemotherapy regimens

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

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

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

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

These are usually followed by a stem cell transplant.

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

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.

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.

More intensive regimens include:

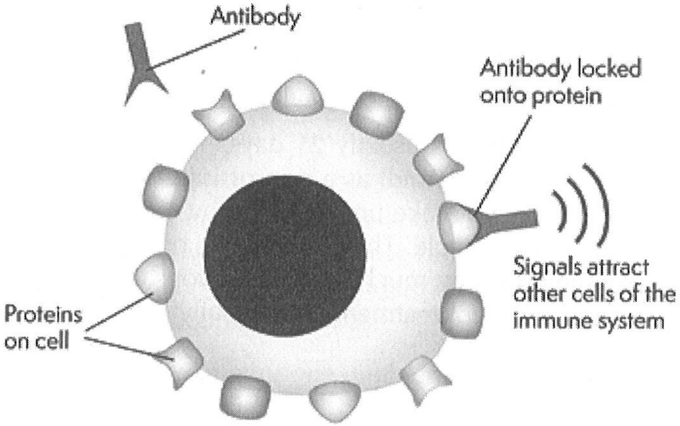
- **DA-EPOCH:** **d**ose-**a**djusted **e**toposide, **p**rednisolone, vincristine (**O**ncovin®), **c**yclophosphamide and doxorubicin (or **h**ydroxydaunorubicin)
- **CODOX-M:** cyclophosphamide, vincristine (**O**ncovin®), **dox**orubicin and **m**ethotrexate; this is sometimes alternated with IVAC
- **IVAC:** **i**fosfamide, etoposide (also known as **V**P-16) and cytarabine (also known as **A**ra-**C**)
- **MATRix:** **m**ethotrexate, cytarabine (also known as **A**ra-C), **t**hiotepa and **ri**tu**x**imab.

Antibody therapy for non-Hodgkin lymphoma

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.



Antibodies stick to specific proteins on a cell

Having antibody therapy

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

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

- If you are having rituximab with chemotherapy, you have it on the first day of each treatment cycle.
- If you are having rituximab on its own, you usually have it once a week for 4 weeks.

- If you are having obinutuzmab with chemotherapy, you have it on day 1, day 8 and day 15 of your first treatment cycle. After this, you have it on the first day of each treatment cycle.

Before you have antibody therapy, you have medicines such as antihistamines and steroids to help prevent any reactions to it. You then have the antibody therapy through a drip into a vein. You have your first dose slowly. It might take a few hours. You have the rest of your doses more quickly unless you have serious side effects the first time. If you are having rituximab, you might have it as an injection under your skin (subcutaneously) after the first dose.

The most common reactions to antibody therapy are shivers, fevers and flu-like symptoms. This is called an 'infusion reaction'. It is more likely to happen with your first dose, which is why you have it more slowly.

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

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.

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 for non-Hodgkin lymphoma

Radiotherapy uses high-energy X-rays and other types of radiation to kill cancer cells. The high-energy radiation is directed to precise areas of your body so it is usually used to treat lymphoma that is only in one or two places rather than spread throughout your body.

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

Radiotherapy might be used to treat early stage low-grade non-Hodgkin lymphoma that is only affecting one part of your body. In some cases, this can cure the lymphoma.

Radiotherapy might also be used to treat advanced stage lymphoma if there are particular areas of lymphoma that are causing problems.

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 chemoimmunotherapy
- 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.

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

Stem cell transplant for non-Hodgkin lymphoma

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
- primary CNS lymphoma .

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.

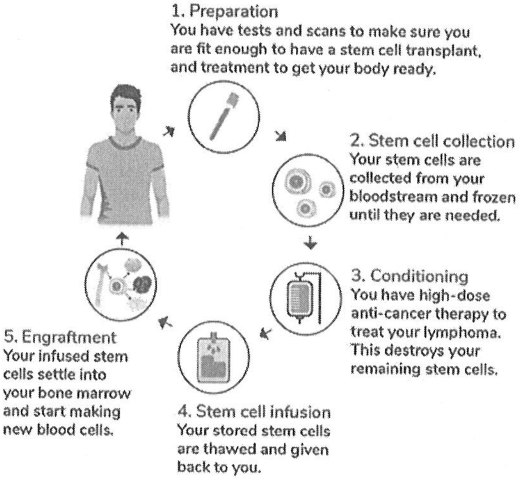
Having a stem cell transplant

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.

Autologous stem cell transplant process

We have separate information on stem cell transplants, including a book on autologous (self) stem cell transplants.

Maintenance therapy

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

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

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

Treatments for symptoms and side effects

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

Medicines to help with side effects

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

Steroids

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

Sometimes, steroids can be given before starting definitive chemotherapy as prephase to reduce the lymphoma bulk.

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

Blood transfusions

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

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 if they drop too much during chemotherapy.

The growth factor most commonly used is called 'granulocyte-colony stimulating factor' (G- CSF). You have G-CSF as an injection into the fatty tissue under your skin (a subcutaneous injection), usually into your tummy, the top of your leg or the top of your arm. You (or a friend or family member) might be taught how to give yourself the injections at home. Alternatively, a community nurse might visit you to give you your injections. You must keep G-CSF in the fridge.

The injections can sting and you might have side effects such as flu-like symptoms, fevers, bone pain or headaches. Mild painkillers such as paracetamol can help, but ask your medical team before you take anything. If you feel unwell during your treatment, contact your hospital straightaway.

Plasmapheresis

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

Coping with treatment

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.

Each person gets slightly different side effects, even if two people are having the same treatment.

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. Your medical team should discuss this with you before you start treatment.

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

Low blood counts and risk of infection

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

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

You have regular blood tests to check your blood counts.

Low neutrophil count

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

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

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 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 lower your infection risk

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

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

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.

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. They might ask you for a stool (poo) sample to make sure you don't have an infection.

Tips to help bowel problems

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

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

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

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

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

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

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

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.

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.

Tumour lysis syndrome

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.

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 social worker might be able to help you access this.

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

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.

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

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

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

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

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

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

What happens if non-Hodgkin lymphoma comes back or doesn't respond to treatment?

What is relapsed or refractory lymphoma?

Most types of 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).

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

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

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.

What happens if lymphoma relapses?

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

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

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

Transformation

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

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

Coping with the fear of relapse

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

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

Tips for coping with the fear of relapse

- Ask your medical team what signs of relapse to look out for.
- Talk to family, friends or other people affected by lymphoma.

- Consider talking through your fears with a professional, for example a counsellor.
- Try to stay active and do things you enjoy.

How is relapsed or refractory low-grade and high grade non-Hodgkin lymphoma treated?

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

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

Low-grade non-Hodgkin lymphoma

Your medical team might discuss several different treatment options with you. Low-grade lymphoma grows slowly and you don't usually need to start treatment urgently.

Active monitoring ('watch and wait')

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

More chemo-immunotherapy

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

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

Targeted therapies

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

Lenalidomide

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

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

Lenalidomide is also licensed to treat relapsed or refractory mantle cell lymphoma.

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

Idelalisib

Idelalisib targets a protein called 'PI3K' on the surface of B cells. This blocks the signals that help B cells stay alive and divide. Blocking these pathways can make lymphoma cells die. You might be offered idelalisib if you have follicular lymphoma that has relapsed more than once.

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

Ibrutinib

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

You might be offered ibrutinib if you have relapsed or refractory mantle cell lymphoma or Waldenström's macroglobulinaemia.

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

Stem cell transplant

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

Radiotherapy

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

Clinical trials

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

High-grade non-Hodgkin lymphoma

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:** **g**emcitabine, **d**examethasone + cisplatin (**P**latinol®)

- **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 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.

Brentuximab vedotin

If you have relapsed or refractory anaplastic large cell lymphoma (ALCL), you might have treatment with a targeted drug called brentuximab vedotin. 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.

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.

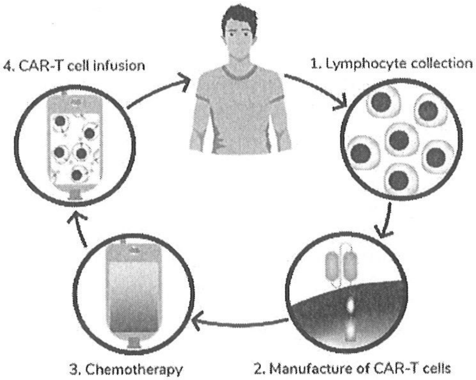
First you have medicines to help prevent any reactions to the drug. Then you have polatuzumab vedotin through a drip into a vein. It takes about 90 minutes.

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.

What happens if lymphoma relapses again?

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

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

If your lymphoma comes back repeatedly, your treatment options are more limited because it is unlikely that the treatment you've had before will be beneficial. Together, you and your medical team may decide whether to continue with treatment or whether to concentrate on your quality of life. There are lots of palliative care options to control your symptoms and to keep you well (and out of hospital) for as long as possible.

What happens after treatment?

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.

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.

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.

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.

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.

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.

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 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.

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.

Living with and beyond lymphoma

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.

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.

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.

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.

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.

When someone close to you has lymphoma

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

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

You probably have many of the same emotions as your loved one. Talk to someone – friends, family, or a specialist – especially if you are finding it hard to cope.

People are often unsure what to say to someone affected by cancer or worry that they might say the wrong thing. Often, you don't need to say anything – a smile or a hug may say much more. Let the person with lymphoma know that you love them. Just being ready to listen can be a huge help.

Things you can do to help your loved one include:

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

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Glossary

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

Anaemia shortage of red blood cells or haemoglobin in the blood

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

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

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

Autologous the use of your own tissues or cells, rather than a donor's

B symptoms fever (temperature above 38°C), night sweats and unexplained weight loss

Bone marrow the spongy material at the centre of larger bones where blood cells are produced

Central nervous system (CNS) your brain and spinal cord

Chemotherapy treatment that uses drugs to kill cancer cells; 'chemo' for short

Chemotherapy a combination of chemotherapy drugs given at a particular dose regimen and schedule

Cycle a round of treatment followed by a rest period to allow your body to recover before the next round of treatment

Extranodal outside the lymph nodes

HIV human immunodeficiency virus: the virus that causes AIDS

Immune system the system in your body that fights off and prevents infection

Immunotherapy treatment that helps your immune system recognise and destroy cancer cells

Intrathecal injection given into the fluid around your spinal cord

Late effects side effects that can develop months or years after treatment

Lumbar puncture a test that involves taking a sample of the fluid around your spinal cord to be examined under a microscope

Lymph nodes small, bean-shaped structures spread throughout your lymphatic system that filter lymph

Lymphatic system a network of tubes, nodes and organs that filters out germs and toxins, helps destroy cells that are old or damaged and drains waste fluids from your tissues

Lymphocytes specialised white blood cells that are part of your immune system; the cell that becomes cancerous in lymphoma

Neutropenia shortage of neutrophils in the blood

Neutrophils a type of white blood cell that is important in fighting infections

Peripheral neuropathy damage to the nerves of your peripheral nervous system, which carries signals between different parts of your body

Platelets tiny fragments of cells in your blood that help your blood clot

Progressive lymphoma lymphoma that gets worse during treatment

Radiotherapy treatment that uses radiation to kill cancer cells

Red blood cell the type of blood cell that carries oxygen around your body

Refractory lymphoma lymphoma that doesn't respond to treatment

Relapsed lymphoma lymphoma that comes back after responding to treatment

Remission no evidence of disease on tests or scans; 'partial' remission means the disease has reduced but not gone completely

Spleen a pear-sized organ behind your ribcage on the left-hand side; it filters blood

Stage a measure of how much of your body is affected by lymphoma

Stem cells undeveloped cells that can mature into many different cell types; 'haematopoietic' stem cells mature into different types of blood cell

Stem cell a procedure that replaces damaged or destroyed stem cells in transplant your bone marrow with healthy stem cells

Steroid a medicine with anti-cancer effects that also affects your body's response to infection and injuries

Targeted therapies drugs that interfere with particular proteins or biological processes in cancer cells to stop them growing or dividing

Thrombocytopenia a shortage of platelets in your blood

Thymus a small, butterfly-shaped gland behind your breastbone where T lymphocytes develop

Transfusion having blood or blood products given to you through a drip into a vein

Tumour lysis rapid breakdown of tumour cells that releases chemicals that syndrome can damage your kidneys and heart

White blood cell a cell that helps your body fight infections; there are several different types, including lymphocytes and neutrophils

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NOTES

JASCAP is a charitable trust that provides information various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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Contact: **Mr. Prabhakar Rao or Ms. Neera Rao**

JASCAP: We need your help

We hope that you found this booklet useful

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by cheque or D/D payable in Mumbai in favour of "JASCAP".

Important

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