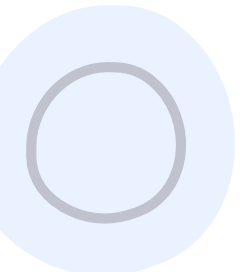
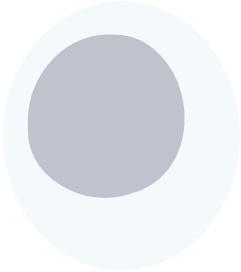




Non-Hodgkin lymphoma (NHL)

A guide for people
with NHL and their
support network

**Leukaemia
Foundation[®]**



This booklet has been written to help you and your support people understand more about Non-Hodgkin lymphoma (NHL).

This booklet has a list of contents, useful resources and a glossary. Your doctor or nurse can answer further questions. You can also call our Blood Cancer Support Coordinators on 1800 620 420.

You will meet many healthcare professionals working as a team to provide you with the best available treatment. You will need to have a regular GP throughout your treatment. In this booklet when we refer to 'your treatment team' we usually mean haematologist and haematology nurses.

There is some information about treatments in this booklet, but it does not recommend any particular treatment. You must discuss your circumstances and treatment options with your haematologist.

The Leukaemia Foundation acknowledges the Traditional Owners of country throughout Australia and recognises their continuing connection to land, sea and community. We pay our respects to their Elders past, present and emerging.

The [Leukaemia Foundation](#) can provide you with additional support and the latest information about your blood cancer.



Booklets for Aboriginal and Torres Strait Islander patients and their families can be found on our [website](#).

Access the Leukaemia Foundation [online support service](#) for practical and emotional information and resources.



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NHL in brief

About NHL

NHL is a group of cancers of the lymphatic system. It is a cancer of white blood cells of the immune system called lymphocytes (B-cells, T-cells, and natural killer cells). NHL can affect a single lymph node or a group of lymph nodes. It might affect other parts of the body where there is lymphatic tissue, such as the spleen, liver or bone marrow.



Symptoms of NHL include:

- Tiredness
- Weight loss
- Drenching night sweats
- Susceptibility to infection
- Itching all over
- Swollen lymph nodes
- Enlarged organs (like the spleen)



NHL is diagnosed through:

- Blood tests
- Lymph node biopsy
- Scans
- Bone marrow biopsy

Treatment includes observation, chemotherapy, immunotherapy, and radiotherapy. Some people have a stem cell transplant. Treatments for NHL are constantly developing, new treatments may be delivered as part of a clinical trial.

In most cases, we don't know what causes NHL. There are usually one or more mutations in (changes to) the genetic material of white blood cells called lymphocytes. There are some known risk factors. There is no way to prevent NHL and you can't catch it.

Who gets NHL?



6600

number of Australians diagnosed each year



78%

of people diagnosed are over 60



68

average age at diagnosis

Second opinion

If you feel unsure about your diagnosis or treatment, you are entitled to seek a second opinion from an independent doctor. This may be at the same hospital or clinic, or at a different location. If you feel overwhelmed, then you might benefit from speaking with someone at the Leukaemia Foundation, your GP, or a counsellor for advice.

“Your guide to best cancer care” is a resource to help guide you, your family and friends through the blood cancer experience. There are specific guides for each type of blood cancer.

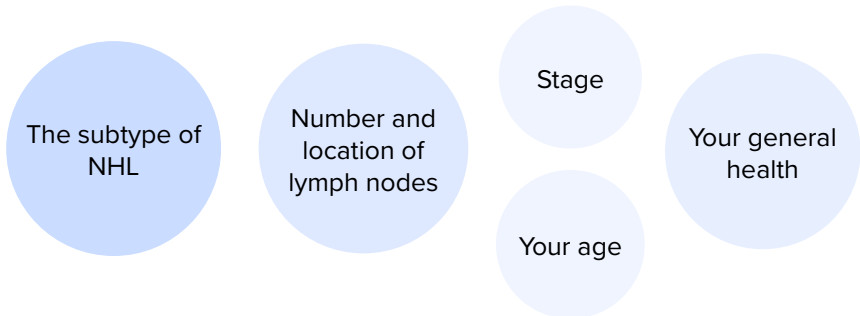
Access the Best Cancer Care guides
at cancer.org.au



What's the prognosis?

A prognosis is an estimate your haematologist makes of the likely course and outcome of your disease. The International Prognostic Index calculator may be used to determine your outcomes.

Your haematologist will take into account many factors when considering your prognosis. **These include:**



An average prognosis is taken from many patients with similar characteristics. They are limited in predicting outcomes for individual patients.

All about blood

What is blood?

Blood travels through the heart and blood vessels, carrying oxygen, nutrients and waste products. It's made up of cells and plasma. Plasma is the straw coloured liquid part of the blood that carries blood cells and other substances around your body. The main types of blood cells are red and white cells. Platelets are talked about like blood cells, but they are fragments of blood cells.



Red blood cells

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives the blood its red colour and carries oxygen from the lungs to all parts of the body. Most blood cells in your total blood volume (40-45%) are red blood cells. They carry oxygen for the body to produce energy.



White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs. They form part of the immune system. White blood cells are necessary to protect us against and fight off infection.



Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They stick together when you are bleeding to help your blood clot, a process called coagulation.

Where and how is blood made?

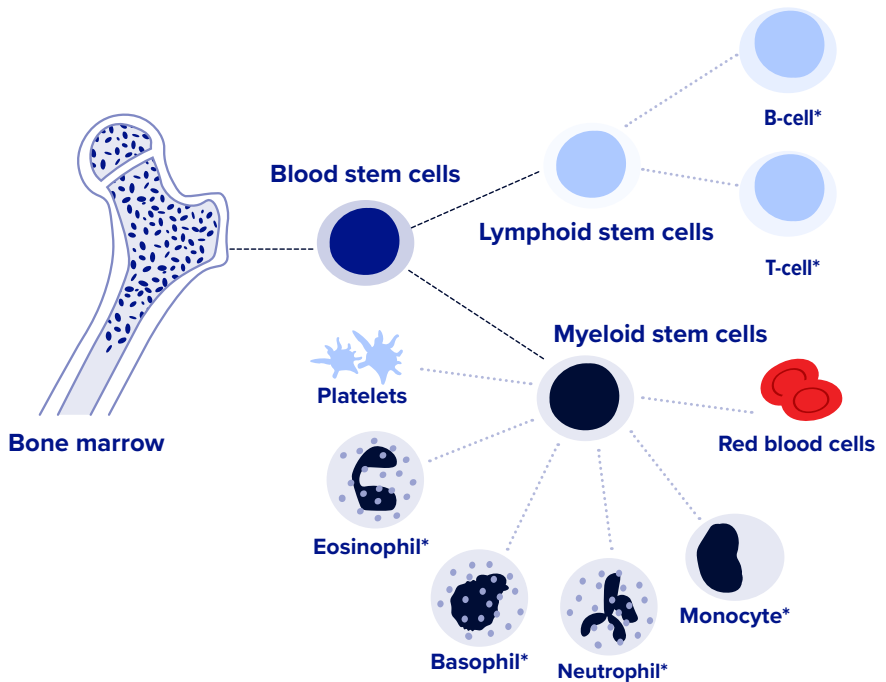
Bone marrow

Bone marrow is spongy tissue in the middle of certain bones. Most blood cells are made in your bone marrow. This process is called haemopoiesis.

In children, haemopoiesis takes place in the long bones, like the thigh bone (femur). In adults, it's mostly in the spine (vertebrae), hips, ribs, skull and breastbone (sternum). You may have a bone marrow biopsy taken at the back of your hip (the iliac crest).

Think of blood production like a family tree. At the top of the tree are the blood stem cells, which are the youngest (most immature) blood-forming cells. They can make copies of themselves and new cells.

There are two types of progenitor cells that split the family tree: lymphoid cells and myeloid cells. At the bottom of the family tree are red blood cells, white blood cells*, and platelets.



Growth factors

All normal blood cells live a short time:



They then die off and are replaced by new cells from the bone marrow. This means that your bone marrow remains very busy throughout your life.

Chemicals in your blood, called growth factors, control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

Some growth factors can be made in the laboratory (synthesised) and given to people to help treat blood disorders.

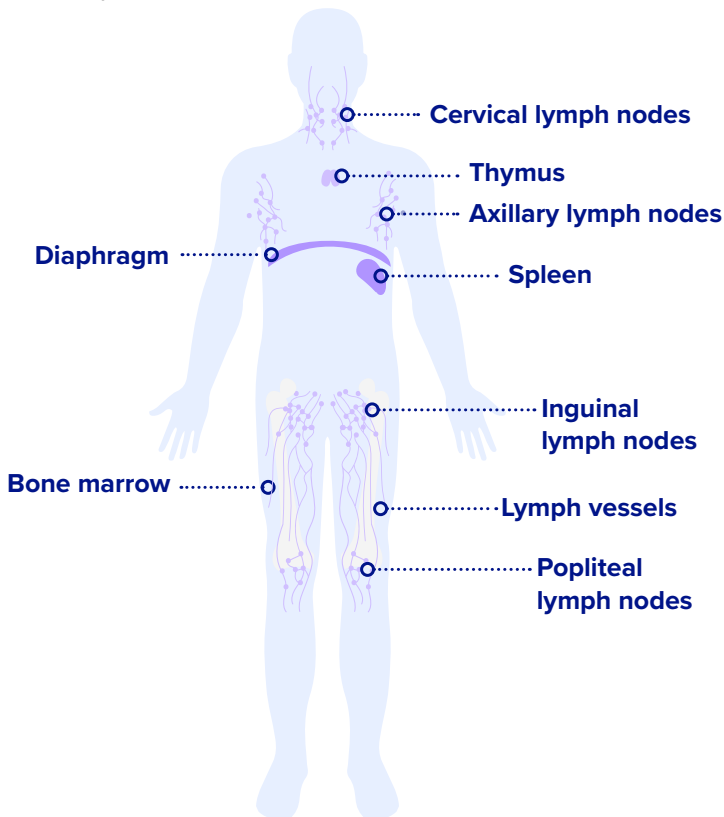
All about the lymphatic system

The lymphatic system plays various roles in your immune system and helps defend our bodies against infection and disease. It's a network of small tubes called lymphatic vessels. These carry lymph around the body. It also drains lymph fluid that's leaked from blood vessels into your body's tissues and returns it to the blood.

The lymphatic system is made up of:

- Lymphatic vessels
- Lymph nodes (also called lymph glands)
- White blood cells (lymphocytes)

Lymph nodes are small filters. They filter bacteria from the lymph fluid. Lymphocytes (white blood cells) inside the lymph nodes attack and kill bacteria. Your neck, armpits, and groin area all contain groups of lymph nodes. There are also some along the lymphatic pathways in your chest and belly.



Lymphatic tissue is also found in:

- The spleen (an organ on the left side of the abdomen)
- The thymus (a gland behind the breast bone)
- Tonsils and adenoids (glands in the throat)
- Bone marrow
- The stomach and gut
- The skin

All about lymphoma

Lymphoma is a group of cancers that develops in the lymphatic system.

There are two main types of lymphoma:

- Non-Hodgkin lymphoma
- Hodgkin lymphoma

There are more than 80 subtypes of NHL and five subtypes of Hodgkin lymphoma. The factors that make up lymphoma subtypes are defined by the World Health Organization (WHO).

As there are many subtypes of NHL, your experiences and expectations may differ in comparison to others. Identifying the correct subtype is very important in determining your prognosis and treatment.



All about NHL

What is NHL?

NHL is a group of cancers of the lymphocytes (B-cells, T-cells, and NK cells). NHL can affect a single lymph node or a group of lymph nodes. It may also be in another part of the body where there is lymphatic tissue, such as the spleen, liver or bone marrow. In advanced stages, NHL can spread through the lymphatic system and the blood to almost any part of the body.

Subtypes of NHL

The many NHLs are divided into two groups:

B-cell lymphomas
(affect developing
B-cells)

T-cell lymphomas
(affect developing
T-cells)

NHL is also described by how fast it grows.

Low-grade or indolent lymphomas are slow-growing and may grow slowly over many years. People diagnosed with low-grade lymphomas may not have symptoms and may not need treatment.

Intermediate-grade and high-grade lymphomas are usually aggressive and grow fast. They may cause severe symptoms, and usually need to be treated soon after diagnosis.

Common types of NHL

Slow-growing (indolent/low grade)

Cutaneous T-cell lymphoma (CTCL)
Low grade follicular lymphoma (FL)
Marginal zone B-cell lymphoma (MZL)
Waldenstrom's macroglobulinaemia (WM)
Small lymphocytic lymphoma (SLL)
Indolent mantle cell lymphoma (iMCL)
Mucosa-associated lymphoid tissue (MALT) lymphoma

Aggressive (intermediate/high grade)

Anaplastic large-cell lymphoma (ALCL)
Burkitt's lymphoma
Diffuse large B-cell lymphoma (DLBCL)
Lymphoblastic lymphoma
Peripheral T-cell lymphoma
Blastic mantle cell lymphoma

You can find more information about subtypes of NHL on our [website](#).



The WHO has a system that defines (classifies) the subtypes. The classifications are based on:

- Which cell is the original type of cell affected: B-cells, T-cells or NK cells
- What the lymphoma cell looks like under a microscope
- Where the lymphoma cells are found in your body
- Any genetic or chromosome problems (abnormalities)

Your haematologist will use the WHO system to work out which subtype you have and the right treatment for you.

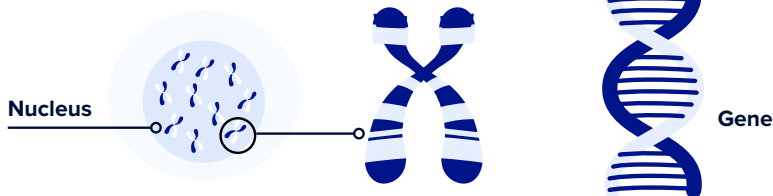
How does NHL develop?

Lymphomas start in developing white blood cells called lymphocytes in the lymphatic system. The three types of lymphocytes are B-lymphocytes (B-cells), T-lymphocytes (T-cells), and Natural killer cells (NK cells).

These cells have undergone a cancerous change. They multiply and divide abnormally to form tumours.

Tumours are collections of cancer cells. They cause swelling in the lymph nodes and other parts of the body. Cancerous lymphocytes (called lymphoma cells) crowd normal lymphocytes. Then the immune system becomes weak and can't function properly. Lymphocytes may also crowd the bone marrow and prevent it from making normal blood cells.

Inside cells there are coded instructions that control how the cell should act. Chromosomes inside cells are long strands of deoxyribonucleic acid (DNA). Each section of DNA that holds the cell's instructions is called a gene. Lymphocytes become lymphoma cells due to genetic changes (called mutations) within the cells.



Cell

The nucleus controls the processes of the cell.

Chromosome

Chromosomes are thread-like structures made up of DNA tightly coiled many times around proteins called histones.

DNA

Deoxyribonucleic acid is a self-replicating material present in nearly all living organisms as the main part of chromosomes. It is the carrier of genetic information.

Causes of NHL

In most cases, there is no specific cause of NHL. Gene mutations in cells happen all the time. Healthy cells have clever ways of stopping them from causing problems in the body. There are many gene and chromosome changes linked to NHL. Why a particular person, at a particular time, gets a certain type of NHL is not really known. There are some things (risk factors) that increase a person's risk of developing NHL.

Known NHL risk factors

Viruses:

Epstein-Barr virus (causes glandular fever)
T-cell lymphotropic virus (HTLV-1)
Human immunodeficiency viruses (HIV)
Hepatitis C

A weak immune system: including medications used to suppress immunity after a transplant.

Autoimmune diseases:

Rheumatoid arthritis (RA)
Systemic lupus erythematosus (SLE)
Sjogren disease

Long-term bacterial infections:

Helicobacter pylori Coxiella burnetii
Chlamydia psittaci Borrelia burgdorferi
Campylobacter jejuni

Exposure to high levels of some environmental chemicals, especially benzene and petroleum products.

Close relative with NHL: having a close family member (parent or sibling) with NHL.

Radiation exposure: previous radiation therapy, or accidental exposure to high levels of environmental irradiation.

Textured breast implants: some women with ‘textured’ breast implants can develop a rare breast implant associated Anaplastic large cell lymphoma (BIA-ALCL).

Dietary intake: a diet high in meat and fat.

Symptoms of NHL

Some people with NHL have no symptoms at all. It may be picked up during a routine blood test or scan.

You may have general symptoms, such as:

- Fatigue (extreme tiredness not relieved by rest)
- Weight loss for no reason
- Lack of appetite
- Fever
- Drenching night sweats
- Itching all over that doesn’t go away
- Skin rash

B symptoms: Drenching night sweats, fever, and loss of more than 10% of your body weight over six months are sometimes called ‘B symptoms’. Their presence may help with prognosis and staging of your lymphoma.



Sometimes lymphoma starts in the lymph nodes or tissues in deeper parts of the body. If you have it in:

- **The belly** (abdomen); you may have gut pain or feel swollen.
- **The spleen;** you may have abdominal pain and feel full after only a small meal.
- **The groin;** you may have swollen legs.
- **The chest;** you may cough and find it hard to breathe.
- **The brain;** you may have symptoms like a stroke.

Swollen lymph nodes

You may feel small, hard lumps in your armpits, on either side of your neck, and/or in your groin. There are internal lymph nodes in your chest and belly. They might swell but can only be seen with scans.

Enlarged spleen and/or liver

Your spleen is an organ near your ribcage in the top left of your belly (abdomen). It contains lymphatic tissue. When the spleen is swollen (enlarged), it is called splenomegaly. Splenomegaly causes a fullness, discomfort or pain in the abdomen on the upper left side. People with splenomegaly often feel full after eating small amounts.

The liver is an organ near your ribcage on the top right of your abdomen. The liver contains lymphatic vessels and nodes. Lymphoma can cause the liver to swell, this is called hepatomegaly. Hepatomegaly causes similar symptoms to splenomegaly. But the symptoms are on the upper right of your abdomen.

Low blood counts

Many symptoms of NHL are a result of blood cell counts below the normal range. If the lymphoma cells are crowding your bone marrow it can't make enough healthy cells.

You may have lower-than-normal numbers of red blood cells, white blood cells, platelets, or a combination of these cells.

Anaemia is when you have low red blood cells. Red blood cells are important for carrying oxygen around your body. You may have neutropenia, a low number of neutrophils. Neutrophils are a type of white blood cell that fights and prevents infection. Thrombocytopenia is a low platelet count. Platelets help control bleeding and help wounds to heal. Pancytopenia is when all these blood cell types are low.

Anaemia

Cause

Low RBCs or Hb

You might notice

Tiredness, weakness, pale skin, shortness of breath, heavy legs, difficulty concentrating, feeling lightheaded, rapid or irregular heartbeat.

Neutropenia

Cause

Low WBCs (neutrophils)

You might notice

More frequent or severe infections eg. chest or skin, fevers, shivering, chills, low blood pressure, mouth ulcers.

Hypogammaglobulinaemia

Cause

Low antibodies

You might notice

More frequent or severe infections eg. chest or gut, fevers, difficulty getting over infections.

Thrombocytopenia

Cause

Low platelets

You might notice

Easy bruising and bleeding e.g. nosebleed, cuts that keep bleeding, coughing up blood, petechiae - tiny unraised red blood spots under the skin, often starting on the legs.

Pancytopenia

Cause

All three blood cell types are low

You might notice

A mix of symptoms from all three conditions

How is NHL diagnosed?

Your doctor will discuss your symptoms, look at your blood, scan, and biopsy results. Some symptoms of NHL are similar to many other conditions. You will need several tests before lymphoma is diagnosed.

Medical history and physical exam

Your treatment team will take a full medical history:

- Past and present illnesses
- Health problems
- Infections
- Bruising and bleeding
- Details of any medications you have taken, are taking or intend to take. These include prescribed and over the counter medications.
- Do a physical examination, to check your general health and any signs of NHL (like swollen glands/swelling in your belly, chest, neck, armpits, and groin).

Full blood count

You will be asked to have a simple blood test called a full blood count (FBC). This test measures the number of red cells, white cells and platelets in circulation. Your treatment team will give you a referral and tell you where to go to have it done. They will also tell you if you need to fast (not eat or drink) for a certain amount of time before you have the blood test. A pathologist (blood specialist) will look at the blood cells under a microscope.

Blood chemistry tests

Blood chemistry tests measure the levels of different chemicals in your body. These blood tests will often be taken at the same time as your FBC.

Some blood tests taken may include:

- Hepatitis and HIV tests: hepatitis B can become active again due to cancer or some of its treatments. HIV and hepatitis C may affect your treatment.
- Antibody testing: depending on the type of NHL you have and treatments you have received, you may have low or high levels of antibodies. Low antibody levels may increase your risk of infection.

Substance Tested	What it indicates
Creatinine	Kidney function
Electrolytes	Kidney function
Blood urea nitrogen (BUN)	Kidney function
Calcium	Bone destruction
Lactate dehydrogenase (LDH)	Blood cell damage
Beta-2 microglobulin	Level of lymphoma in the body

Lymph node biopsy

A lymph node biopsy is a procedure where part or all of a lymph node is removed. The procedure is performed in the day surgery or radiology (imaging) department of a hospital. A local anaesthetic, gentle sedation or general anaesthetic will be given depending on the biopsy site.

A core biopsy is a sample taken with a needle, this will take around 30 minutes. An excisional biopsy is a minor operation where part or all the lymph node is removed. The type of anaesthetic depends on where in the body the lymph node or in some cases affected tissue is located.

Your treatment team will tell you how to prepare for your biopsy. You may need to fast (not eat or drink) for some time if you require sedation or an anaesthetic. You will be able to go home the same day but shouldn't drive, so arrange transport home.

Your lymph node sample is sent to the laboratory. A specialist doctor (pathologist) will look at the lymph node cells under a microscope. Several other tests may be performed on the biopsy. These include checking for mutations and looking at the lymphocytes with a laser analyser ('flow cytometry'). You may have to wait several days to a week for the initial results of the biopsy.

In some cases, the biopsy may not provide enough information to diagnose lymphoma and/or the subtype. You may need to have a repeat biopsy. This may be from another site or a larger sample of the lymph node is taken. It is important that adequate tissue is taken during the biopsy to ensure accurate diagnosis. This is very important in determining the best course of treatment.

Disease staging

The stage of your lymphoma depends on where the disease is in your body. Staging is determined by the number of areas in your body affected by lymphoma. This helps with treatment planning and determining prognosis.

There are four stages of NHL:

Stages 1 and 2 - lymphoma is limited to one or two areas of the body. This is called early stage lymphoma.

Stages 3 and 4, the disease is more widespread in the body. This is advanced stage lymphoma.

Stages of lymphoma

Stage 1 lymphoma

Lymphoma is only in one lymph node area, or one organ such as the thymus, or one area of a single organ outside the lymphatic system.

Stage 2 lymphoma

Lymphoma affects two or more lymph node areas either above or below the diaphragm* or extends locally from one lymph node area into a nearby organ.

Stage 3 – 4 lymphoma

Lymphoma is in lymph node areas on both sides of the diaphragm*(stage 3), or the cancer has spread throughout the body beyond the lymph nodes (stage 4).

**the diaphragm is a large muscle that separates your stomach and chest.*

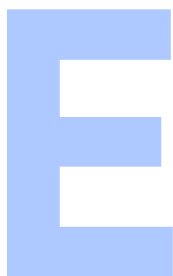
A, B, E or bulky?

Your treatment team may use A, B, E and bulky to describe your lymphoma.



The letter 'A' is used after the stage of lymphoma if you do not have any symptoms. For example, Stage 2A.

The letter 'B' will be used after the stage of your lymphoma if you have symptoms such as fevers, night sweats and unexplained weight loss. For example, Stage 2B.



The letter 'E' describes extranodal, it is used when the lymphoma has spread to an area or organ outside the lymph nodes. For example, Stage 4E. If the extranodal site is the spleen, this may be designated with the letter 'S'.



The term 'bulky' is used if you have an area of lymphoma with a large diameter. Definitions of 'bulky' vary but range from a diameter of 5.5cm - 10cm. Sometimes the letter 'X' is to indicate bulky disease. For example, Stage 3X.

Staging tests

Bone marrow biopsy

Your treatment team may request a bone marrow biopsy to check if the lymphoma is in your bone marrow. This procedure is performed either in hospital, at your haematologist's rooms, in a day procedure unit or an outpatient clinic. It's a good idea to bring a support person with you. They can help you home if you are instructed not to drive afterwards.

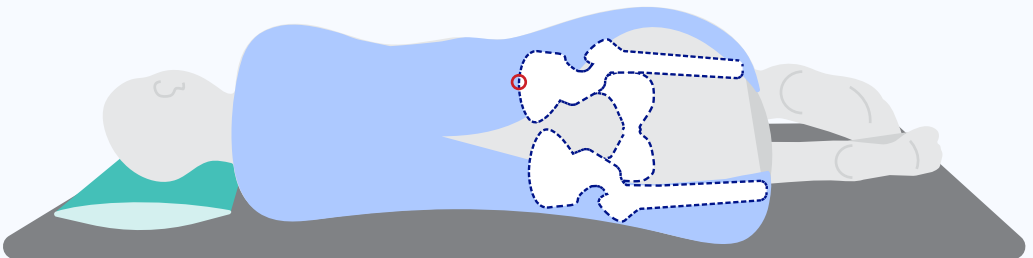
What does a bone marrow biopsy involve?

A bone marrow biopsy involves using a needle to enter the bone marrow at the back of the hip (iliac crest). This is an area where the bone is usually close to the skin and can be easily accessed. A small amount of liquid bone marrow (aspirate) is usually taken and placed onto slides and into blood tubes. The liquid bone marrow is sent to the laboratory for examination and other specialised tests. Usually a small piece of the bone marrow (trephine) is also taken and examined in the laboratory.

Is a bone marrow biopsy painful?

A bone marrow biopsy can cause discomfort and/or pain. Local anaesthetic is injected into the skin and on the bone before the procedure to numb the area. You may also be given a form of pain preventer that you breathe in. On occasions a small dose of intravenous sedative may be required to manage discomfort. This is in the hospital setting, where you will be closely monitored.

The bone marrow is taken from the back of the hip bone, not from the spine.



What to expect afterwards

You should try to rest for the day. If you have had sedation, then you must not drive a car or work for 24 hours, so you will need someone to take you home. If you have any pain or discomfort, take paracetamol as per the recommended dose. The dressing must remain in place for 24 hours after the procedure, or as advised by your treatment team. You will have to wait several days for the results of the bone marrow biopsy.

Special testing

Your haematologist might request additional tests on your biopsy. These tests help your haematologist work out your treatment options.

Cytogenetic tests

Cytogenetic tests are a genetic test performed on the bone marrow. The results provide information about the genetic make-up of your cells. These tests examine the structure of chromosomes (DNA) in your bone marrow cells. This determines if there are any gene mutations. These results help your haematologist diagnose which type of NHL you have, and your treatment plan.

Flow cytometry

Flow cytometry looks for proteins on the surface of a cell. Dye is applied to thousands of cells. This helps to work out the types of cells and the number of abnormal cells.

Flow cytometry uses a laser to look for proteins on the surface of a cell. Every type of blood cell has its own set of proteins, called an immunophenotype. In flow cytometry, dye is applied to thousands of cells. This helps to work out the immunophenotypes and the number of abnormal cells. The immunophenotype can help distinguish between different types of NHL that look the same under a microscope.

FISH

Fluorescent in-situ hybridisation (or FISH) is a specialised cytogenetic test. It uses dyes to highlight parts of chromosomes to check if they are abnormal.

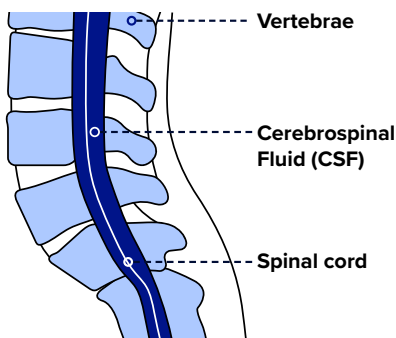
Molecular tests

Molecular genetic tests such as polymerase chain reaction (PCR) or next generation sequencing (NGS) look directly at the genetic sequence/code and help your haematologist work out which type of NHL you have. It may take a few weeks for these test results.

- **Polymerase chain reaction (PCR)** – also called quantitative reverse transcriptase PCR (QPCR). This test evaluates DNA to look for known/specific gene mutations/sequence. It is often done at the same time as cytogenetics/FISH. This test is used to monitor your response once treatment starts.
- **Next generation sequencing (NGS)** – looks for multiple gene mutations across multiple samples at the same time. It can detect unknown mutations/sequence. It is often done at the same time as cytogenetics/FISH.

Lumbar Puncture

Cerebrospinal fluid (CSF) surrounds the brain and spinal cord to protect them. Sometimes NHL can spread to the CSF. If symptoms suggest lymphoma cells have spread to the CSF, you'll need a procedure to take a sample of CSF. This is called a lumbar puncture or spinal tap.



During a lumbar puncture:

- 1 You will either lay on your side with your knees close to your chest or sit bent over a table with pillows (this enables the bones of the spine to spread).
- 2 You will be asked to keep very still and your back will be cleaned thoroughly with antiseptic.
- 3 A small amount of local anaesthetic will be injected into your lower back.
- 4 Once the area is numb, another needle will be put into your back. This is inserted through the skin and between the bones of your spine to reach the CSF.

5

A small amount of CSF will be collected in sample tubes.

6

The needle will be taken out and a dressing will be put on the injection site.

After a lumbar puncture:

- You may be instructed to lie flat for an hour or more after the procedure to prevent a headache.
- You should try to rest for the remainder of the day.
- You may not have any pain but if you do, take paracetamol as recommended.
- You can remove the dressing and shower 24 hours after the test, or as directed by your treatment team.
- The CSF is sent to the laboratory for testing to look at the fluid and find out if it contains lymphoma cells or blood.

If NHL cells are found in the CSF you may be given medication/ chemotherapy directly into the CSF. This is called intrathecal chemo. This procedure is performed through a lumbar puncture, as detailed above. However, once the CSF sample is taken, the medication/chemo is injected through the same needle and then the needle is removed.

HLA testing

Human leukocyte antigen (HLA) testing is also called tissue typing or histocompatibility testing. It tests which HLA genes someone has inherited. A stem cell transplant from a donor (allogeneic stem cell transplant) is an uncommon treatment for lymphoma. However, if you are eligible for an allogeneic stem cell transplant your doctor will request HLA testing. This will be compared to the HLA type of possible donors to see if they match. Autologous stem cell transplants (using your own stem cells) are more common for people with NHL and don't require HLA testing.

You can read more about stem cell transplants later in this booklet, or in our booklet, [‘Allogeneic Stem Cell Transplants’](#).



Imaging tests

A computed tomography (CT) scan, magnetic resonance imaging (MRI) and positron emission tomography (PET) scan show where NHL is in your body. These imaging tests are done in a radiology department and you are able to go home the same day. You will be given detailed instructions on how to prepare for each scan.

CT scans

CT scans use x-rays and a computer to create detailed images of the inside of your body. They can find tiny changes in tissue density (thickness). CT scans can determine what parts of the body are affected by the NHL. You may have a dye called contrast, which is given as a drink or intravenously before your scan. During the scan you lie flat and still on a cushioned table which moves slowly through the CT machine. The CT scanner takes images as the contrast moves through your body.

PET scan

A PET scan is an imaging test that shows the metabolic function of your tissues and organs. It can show both normal and abnormal function. This provides the potential to find disease in its earliest stages. A PET scan helps to stage your NHL in correlation with symptoms and biopsy results.

Before a PET scan you will be given a small and safe dose of radioactive material. This is called a radiotracer, it is attached to glucose and is in the form of an injection. The radiotracer injection is given to you intravenously. You will sit in a chair for about an hour while the radiotracer is absorbed by your organs and tissues. Diseased cells in your body absorb more of the radiotracer than healthy ones do. These are called 'hot spots'. During the scan you lie flat on a cushioned table that slides in and out of the PET scanner. The PET scanner detects the 'hot spots' and produces images of the affected tissue. You will have a PET scan during and after treatment.

MRI scans

Magnetic resonance imaging (MRI) uses a very strong magnet to make 3D images. It is particularly useful for looking at parts of the body like the spinal cord and brain. MRI scans can sometimes show soft tissue more clearly than CT scans. It might give a clearer image of the NHL.

Before the MRI you might have an injection of a dye (contrast) intravenously. This helps to show your soft tissue clearly. The scanner makes a very loud clanging noise, so you will wear headphones to protect your hearing.

Heart tests

Some medicines for NHL can cause heart problems. Before you start treatment, you might have an echocardiogram or heart scan. The test takes pictures of your heart to check how well it pumps blood.

Other tests

You might need more blood tests and imaging tests (x-rays, scans and/or heart tests) when you are diagnosed and throughout your treatment. Some people will have tests that relate to their NHL symptoms and subtype. These tests may include:

The results of your first blood and bone marrow tests provide a baseline of your disease and general health. Your treatment team can then compare later test results against the baseline to track how you are going.

Endoscopy, which checks your upper (a gastroscopy) or lower (a colonoscopy) gastrointestinal tract.

A testicular ultrasound for men who have a testicular lump.

Multidisciplinary team meetings

When your test results are available your case may be presented at a multidisciplinary team (MDT) meeting.

An MDT meeting generally includes:

- Haematologists
- Radiologists (imaging experts)
- Radiation oncologists (radiotherapy experts)
- Pathologists

The pathologist reviews the biopsy for accurate diagnosis of NHL. A repeat biopsy may be requested or further tests ordered on the existing biopsy. The radiologists will review the imaging scans to help clarify the stage. All the information will be checked. The haematologists and radiation oncologists will suggest the best treatment plan.

This process ensures that diagnosis and staging are accurate.

Multiple expert discussion of your case ensures up-to-date treatment recommendations. Cases may be re-presented to monitor treatment response or at relapse.

What happens next?

After diagnosis

When your test results have been reviewed you will meet with your haematologist. Your NHL diagnosis including the subtype, and your treatment plan will be discussed. It is natural to feel scared, confused or sad. You will be given a lot of information; this can be overwhelming. You may feel relieved and reassured that your symptoms have been explained. Ask your haematologist if you need further details and for some written information. It is helpful to bring someone with you to the appointment. A second pair of ears, someone to take notes and ask questions for clarification.

Intravenous access for treatments

Many NHL treatments are given directly into a vein (intravenously, IV). Your bloodstream can be accessed through the peripheral veins in your arms or through a central vein in your chest. Some treatments can only be given through a line into a central vein. Your treatment team will discuss intravenous access with you before you start treatment.

Peripheral intravenous cannula

A cannula is a short, thin plastic tube with an inner thin needle. Your nurse will insert the cannula into a vein, removing the inner needle so only the thin plastic tube remains in the vein. Usually, cannulas are inserted into your lower arm or the back of your hand. The cannula is held in place with a dressing. Your treatment is given through intravenous lines connected to the cannula. These lines are often connected to a pump. Having a cannula inserted may cause discomfort but once it is in place you should have no pain. It can stay in for a few days or be removed after your treatment.

Peripherally inserted central catheter (PICC)

A PICC is a long, thin silicone tube. A specialist nurse, doctor or radiologist will insert it in an outpatient department. The tip of the PICC is inserted into a vein in your upper arm, then threaded into a large vein in your chest. The other end of the PICC is visible on top of your skin on your upper arm. There may be one, two, or three tubes (lumens) visible. Treatment is given through the lumens. The PICC will be secured with a dressing. PICCs can stay in for up to two years. Sometimes PICCs are called central venous access devices (CVADs).

Port

A port is a type of central venous access device (CVAD) that is surgically implanted under the skin in your upper chest. It has a small dome shaped body with a silicone pad in the middle, this is attached to a tube (catheter). The tip of the catheter is inserted into a large vein and sits just above the heart. You can feel the port under your skin but it does not have external tubes. Your nurse will access the port by inserting a short needle into the silicone pad, this is held in place with a dressing. The needle is replaced every 7 days or removed after treatment, before you go home. Ports can stay in for years. Ports are also called infusaports or portacaths.

Other central lines

A central line is a long, thin silicone tube. **It is a type of CVAD.** There are different types of central lines, Hickman® line, central venous catheter (CVC). The tip of the tube sits in a large vein above your heart. The other end comes out of your chest and has one, two, or three tubes (called lumens). It is secured with a dressing. Treatment is given through the lumens. A central line can stay in for years.

Treatment goals and responses

During and after treatment, your treatment team will order blood tests and scans to check how you are going.

The main goal of treatment is cure.

Cure is where there is no evidence of lymphoma and no sign of it reappearing even after many years.

Complete response/remission is where the treatment has been successful. It means so much of the lymphoma has been destroyed it can no longer be detected using available tests. The length of time a remission lasts varies from person to person. The lymphoma can come back, even after a long time.

Partial response/remission is where following treatment the lymphoma is less than half its original. Some disease remains in the body.

Stable disease is where the lymphoma is stable and is not getting any better or worse with treatment.

Resistant or refractory disease is where the lymphoma is not responding to treatment.

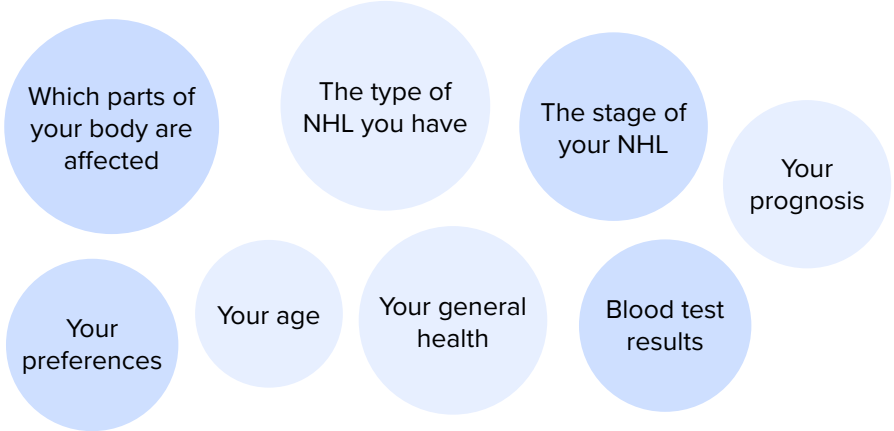
Relapse is where the lymphoma comes back after a remission. You may have more treatment and get into a second remission.

Disease progression is where the lymphoma is getting worse, on or off treatment.

Treatment recommendations

Your treatment team will explain the treatments, their benefits, and possible side effects. They will ask you to sign a consent form to agree to the treatment after you have thought about the options.

Your haematologist will recommend treatment based on:



There are a few kinds of treatment for NHL. Your treatment plan may include one or more of them:



Active observation/ monitoring ('watch and wait') involves regular check-ups but no treatment.



Supportive care controls symptoms of NHL, for some subtypes.



Standard drug therapies and targeted therapies such as chemotherapy and immunotherapy.



Radiation therapy



Stem cell transplant replaces bone marrow cells with new, healthy cells.



Clinical trials

Treatment by grades

Indolent lymphomas (low-grade)

Many low-grade lymphomas take years to grow, cause few (if any) symptoms, and don't need to be treated right away. You will have regular check-ups to monitor your lymphoma and general health. If the lymphoma affects a small group of lymph nodes (Stage 1 or 2), you may just have radiotherapy. If the low-grade lymphoma is more widespread in the body, your haematologist will consider:

- Where the lymphoma has spread to
- How large the areas of lymphoma are
- If you have any symptoms
- Your general health

You may have chemotherapy (either in tablet form or intravenously) and/or immunotherapy. Often you may have both treatments together; 'chemo-immunotherapy'. Sometimes treatment with immunotherapy continues after the chemotherapy stops. This is called maintenance therapy. Sometimes low-grade lymphomas develop over time into more aggressive or high-grade lymphomas. This is called transformed lymphoma and is usually managed as high-grade lymphoma.

Intermediate-grade and high-grade lymphomas

Intermediate-grade and high-grade lymphomas grow quickly and treatment is needed at diagnosis. Most people will have chemotherapy and immunotherapy.

Relapsed or refractory (resistant) lymphoma

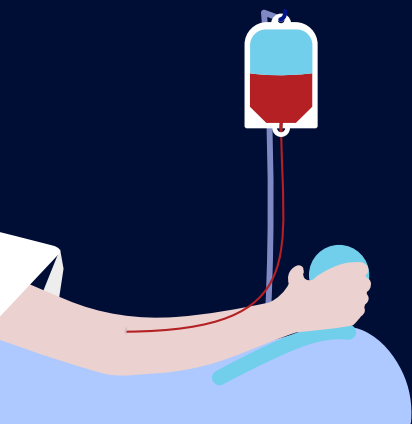
Finding out that your disease has come back or relapsed can be devastating. If your disease does relapse there are usually ways of trying to get it back under control.

This might involve more chemotherapy and/or immunotherapy; changing chemotherapy and/or immunotherapy; or a more intensive or high-dose chemotherapy, followed by a stem cell transplant.

Increasingly, relapsed or refractory lymphoma may be treated with a non-chemotherapy or 'novel' therapy that is specifically designed (or 'targeted') to your particular lymphoma. 'Novel targeted' therapies may be available on the Pharmaceutical Benefits Scheme (PBS) or as part of a clinical trial. If further treatment or a clinical trial is not an option, the treatment goal might change. Your haematologist will speak to you about the best options.

Watch and wait: active observation only

Many people who have indolent (slow growing, low-grade) lymphoma with no symptoms don't need to start treatment. Your haematologist may recommend regular check-ups. Your GP may play an active role in your follow up by monitoring your NHL with blood tests. Follow up timeframes will depend if there are changes in your blood counts, symptoms, or general health. This is called 'watch and wait'.



Supportive care

Supportive care aims to reduce symptoms from your NHL. It includes emotional and social support. The goal is to reduce symptoms of your NHL, but it does not treat the disease itself.

Blood transfusions

You will have regular blood tests to monitor your haemoglobin. Your haemoglobin carries oxygen throughout the body. If your haemoglobin is low and you have fatigue, weakness, shortness of breath and dizziness you may have anaemia. Your treatment team

will assess if you need a red blood cell transfusion. Transfusions are usually given by a nurse in an outpatient department. The nurse will use your CVAD or will insert a cannula into a vein in your arm or hand. Each bag of blood will take 60-120 minutes to transfuse.

Platelet transfusions

If you have symptoms of low platelets (thrombocytopenia), you may need a platelet transfusion. This is similar to a red blood cell transfusion, but you will be given a bag of platelets instead. A platelet transfusion usually takes 30 minutes. There are oral medications that can increase your blood clotting, these may be prescribed by your treatment team.

Growth factors

Growth factors are chemicals in your blood that help the bone marrow produce different types of blood cells. Some growth factors can be made in the laboratory. They are used to boost low blood counts.

Neutrophils are white blood cells that help fight infections. A growth factor called granulocyte colony stimulating factor (G-CSF) makes the bone marrow produce more neutrophils. G-CSF is commonly given to people having chemotherapy. Growth factors are usually given as an injection under the skin (subcutaneous). A family member or friend can be taught to give the injections. The injections can be given at a local medical centre or outpatient department if preferred.

Some people experience flu-like symptoms while using G-CSF including:

- Mild to severe bone pain
- Fevers and chills
- Headaches

Antibiotics

When your white blood cell count is low you have a higher risk of infection. If you develop signs or symptoms of infection, it is important you are treated as soon as possible. Your treatment team will prescribe antibiotics, usually intravenous (IV). You will continue on antibiotics until the infection resolves and your white blood cell count recovers.

Antimicrobial, antifungal and antiviral medicines

When you start chemo you may be given antimicrobial, antifungal and/or antiviral medicines. If you're low in certain cell types, you have a higher risk of fungal or viral infections. These types of medicines will be taken to prevent infection. This is called prophylaxis, or you might hear the drugs referred to as prophylactics. They will usually be in tablet form and your treatment team will tell you how often and for how long you need to take them.

Vaccines

Vaccines are important for people with NHL because you have a higher risk of infection. Vaccines help prevent infections. Inactivated vaccines are the safest and you should not have any live vaccines. You will need to check with your treatment team for the best timing.

Standard drug therapies

Your treatment team might use the term 'standard of care' or 'standard therapy'. This is a treatment that is commonly used by medical experts for a certain type of disease.



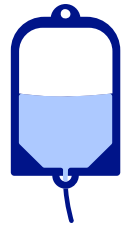
Chemotherapy

Chemotherapy (chemo) is cytotoxic, or 'cell killing', medication that stops cancer cells growing. They work by killing cancer cells, or by stopping them from dividing, replicating, and reproducing. Chemo does damage normal cells, but these cells can repair and recover. Chemo treats disease and is often called disease modifying treatment. Chemo can be given as a tablet, injection, or intravenous (IV) drip.

The type of chemo given depends on the type of NHL. It is common to be on more than one chemo at a time. Some people have chemo alongside other therapies like immunotherapy, surgery, or radiation therapy. You can take chemo tablets at home, or you might have injections or IV chemo in an outpatient ward/clinic, or as an inpatient in hospital. Chemo is given in cycles of treatment days. This means that you will have treatment for a certain number of days, followed by a set number of rest days. The number of treatment days and the number of cycles can be different due to the chemo or the cancer being treated.

Your haematologist will recommend chemo depending on:

- Your type of NHL
- Your overall health
- Your age
- Your preferences



Chemotherapy side effects

Chemotherapy kills cells that multiply quickly, like the cells that cause NHL. It also damages fast-growing normal cells, like hair cells and the cells in your mouth, gut and bone marrow. You get chemo side effects because of the damage to normal cells.

Everyone gets different side effects with chemo. You may have no side effects, or one or more of them, and they may change over time. Your treatment team will have medicines and suggestions to help manage side effects.

Which side effects you have and how severe they are depend on:

- Your type of NHL
- The type of chemotherapy you are given
- Your overall health and wellbeing

You can find more information on chemo side effects and how to manage them on our [website](#).



Changes in blood counts

Chemo affects the ability of your bone marrow to produce enough blood cells. Your red blood cells, white blood cells and platelets will usually drop within a week of treatment. They should then increase before your next cycle of chemo.

Low red blood cells cause anaemia. You may feel tired, short of breath, and look pale. Take it easy and contact your treatment team if you have any concerns. You might need a transfusion.

If your platelets are low you can bruise and bleed more easily. When your white blood cell count is too low you are at higher risk of developing an infection. It is important that you follow the advice of your treatment team immediately if you have signs of an infection.

Risk of infection

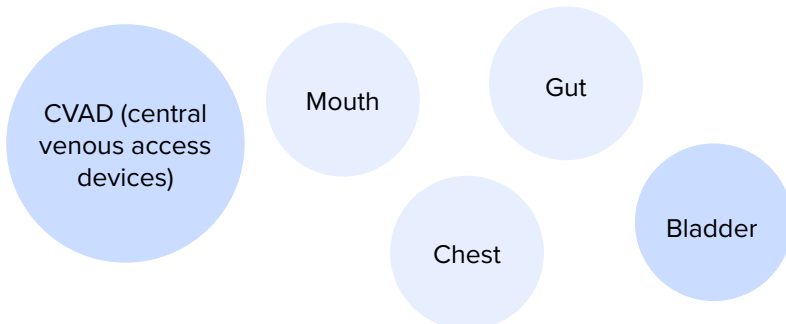
When white cells (neutrophils) are low this increases the risk of developing an infection. A person with a low neutrophil count is described as being neutropenic. The lower the neutrophil count and the longer it is low increases the chance of developing an infection. If you develop a fever (rise in your body temperature) while neutropenic you have 'febrile neutropenia'.



It is important that you follow the advice of your treatment team if you:

- Have a temperature
- Are feeling hot, cold or shivery
- Develop a cough, pain or soreness

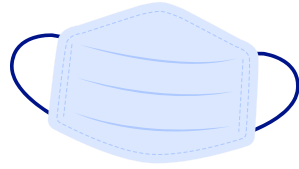
Infections can develop anywhere, common sites of infection include:



Causes of infections include bacteria, viruses and fungi. You may be prescribed preventive antibiotics, anti-viral and anti-fungal medication.

Things you can do to prevent infection:

- Regular hand washing.
- Daily showering.
- Regular mouth care.
- Avoid people with suspected colds, flu and other viruses.
- Avoid close contacts and people with chicken pox, measles or other viruses.
- Avoid people who have had a live vaccines such as polio.
- Avoid places with large numbers of people.
- Wear a mask.
- Avoiding garden soil and potting mix.
- Washing your hands after handling animals.
- Discuss vaccinations with your treatment team.



You can find more information on infection prevention on our [website](#).



Feeling sick - nausea and vomiting

Nausea (feeling sick) and vomiting are common side effects, you will be given medicine to prevent or manage them. If you feel nauseous, even with medicine to help, contact your treating team to ensure it is managed so you can continue to eat and drink. If you are finding it difficult to eat, are eating less than usual and/or losing weight, talk to your treatment team. They can arrange for you to see a dietitian for some advice.

Sense of taste and smell

Changes to your sense of taste and smell can stop you from enjoying food and drinks that you used to love. You might have a metallic taste in your mouth. These changes will pass when your treatment ends.

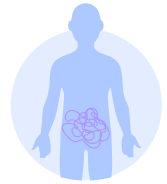


Mouth problems - mucositis

Your mouth or throat might become sore, or you might get ulcers. This is called mucositis. It is very important to keep your mouth clean by using an alcohol-free mouthwash, salty water or sodium bicarbonate in water.

Bowel changes

Chemo can damage the lining of your bowel, this can cause cramping, wind, bloating and/or diarrhoea. You will be given medication to help. Tell your treatment team if you have diarrhoea, are constipated (painful or difficulty when passing faeces), and if you have haemorrhoids. Your treatment team can give you tips on food choices.



You can read more about diet and nutrition later in this booklet and on our [website](#).



Feeling tired and weak (fatigue), even after resting

Most people feel tired following chemo. It can be frustrating if you're used to keeping busy.

You can find more on how to manage fatigue later in this booklet and on our [website](#).



Chemo brain

You may find it difficult to concentrate ('foggy brain') or have trouble remembering things. It can take up to a year after treatment finishes to recover. There are no medicines to help with chemo brain and in some cases changes can be permanent. You can set up some ways to remember things, like writing them down. Talk to your support network too, so they know what's going on.



Bone, joint or muscle aches and pains

Whilst having chemo you may have muscle aches, headaches, back pain, painful and/or swollen joints. Talk to your treatment team about any pain you are experiencing, they will advise you on what medications to take. It is important that your pain is managed so you can move to perform everyday activities.

Hair loss (alopecia) and thinning

The thought of losing your hair is scary. Hair thinning or loss is a very common side effect of chemo. You might lose your head hair, your eyebrows, and your eyelashes, but it's only temporary. Hair starts to fall out a few weeks after you start treatment and tends to grow back three to six months after it finishes. You might find your scalp is itchy and/or tender as you lose your hair, but this will pass. There are some great wraps, turbans, wigs and beanies available. Your nurse can give you information on where to find them.



Tingling or numbness in fingers and toes (peripheral neuropathy)

Some chemo drugs can affect your nerves, usually in your hands or feet. This is called peripheral neuropathy. Symptoms can start any time during treatment. It might be hard to do up buttons or to grip things. Tell your treatment team if you feel tingling, numbness, burning or pins and needles in your fingers or toes.

Sun sensitivity

Some chemo drugs make you more prone to sunburn. You can go outside, but you will need to avoid direct sunlight. Stay in the shade when possible, wear sun protective clothing and apply sunscreen.



Tumour lysis syndrome

When chemo kills a large number of lymphoma cells, the cells break apart and release their contents into the blood. This can cause irregular heart beats and puts stress on the kidneys, which try to rid the body of these substances. Tumour lysis syndrome is a medical emergency. It can happen during induction (the first phase of) chemo. You will be given fluids and medicines to help prevent it.

Early menopause

Some cancer treatments can affect the normal functioning of the ovaries. This can lead to infertility and an earlier than expected onset of menopause, even at a young age. The onset of menopause in this situation can be sudden and distressing. Hormone changes can lead to many of the classic symptoms of menopause including:

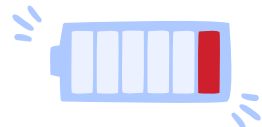


- Menstrual changes
- Hot flushes
- Sweating
- Dry skin
- Vaginal dryness and itchiness
- Headache
- Aches and pains
- Decreased sexual drive
- Anxiety and depressive symptoms

It is important you discuss any changes to your periods with your treatment team. They may refer you to a gynaecologist or clinic for symptom management.

“Manage pain – this affects concentration and energy”

Top tips from people with blood cancer



Tips for managing chemo side effects

Low red blood cells (anaemia)

What might help

You may be given a blood transfusion or recommended supplements.

Low platelets

What might help

- Avoid sharp objects in your mouth like chop bones or potato chips.
- Be careful not to cut or injure yourself.
- Use a soft toothbrush.
- Use an electric razor.
- Wear gloves and closed shoes in the garden.

Low white blood cells (neutrophils) – risk of infection

What might help

- Wash your hands regularly.
- Avoid touching your face.
- Clean surfaces and objects you use often.
- Talk to your treatment team about vaccinations.
- Avoid crowds.
- Keep away from people who are sick and might be contagious (colds, flu, chicken pox).
- Eat food that has been properly prepared and freshly cooked.
- Don't clean up pet faeces.
- Wear gloves in the garden.
- Don't swim in public pools, lakes or rivers.

Feeling sick – nausea and vomiting

What might help

- Eat smaller meals more often during the day.
- Try cool or cold food like jelly.
- Let someone else cook for you.
- Drink ginger ale or soda water.
- Avoid strong smells.
- You'll be given medicine to help.

Change to taste

What might help

- Add a little more sugar to sweet foods.
- Add a bit more salt to savoury foods.
- If you have a metallic taste, try rinsing your mouth out.

Mouth problems – mucositis

What might help

- Use a soft toothbrush and mild toothpaste.
- Brush every time you eat.
- Use salty water, sodium bicarbonate in water or alcohol-free mouthwash.
- Continue to floss but stop if your gums bleed.

Bowel changes

What might help

- Drink plenty of fluids.
- Get some diet advice from your treatment team.
- If you're constipated, don't strain.
- If you have haemorrhoids don't push on them, tell your treatment team, you'll be given medicine to help.

Fatigue

What might help

- See page 55 of this booklet.
- Rest or nap when needed.
- Take regular gentle exercise.

Bone, joint or muscle aches and pains

What might help

- Take medication as prescribed by your treatment team.
- Track your pain, including location and how well pain medication is working.
- Drink plenty of fluids.
- Maintain bone strength through a healthy diet and exercise.
- Rest when needed.
- Breathing and relaxation techniques.
- Use assistive devices if needed, like handrails and walkers.

Chemo brain

What might help

- Keep a notebook or notes app handy to write things down.
- Ask your pharmacist to Webber pack your medications.
- Take regular gentle exercise.
- Socialise – tell your loved ones what's going on/what you're experiencing.

Hair loss and thinning

What might help

- Prepare your family and friends.
- Use a soft hairbrush and a mild baby shampoo.
- Pat your hair dry gently with a towel.
- Cut your hair shorter or have it shaved when you start chemo.
- Use an electric shaver.
- Avoid using heat or chemicals – don't dye or blow dry your hair.
- Use sunscreen on your scalp.

Sun sensitivity

What might help

- Cover up with long sleeves and pants when in the sun/ outdoors.
- Wear sunglasses and a hat or beanie to protect your eyes and scalp.
- Talk to your nurse about which sunscreens are best to use.
- Avoid sun exposure during high UV times of the day.

Corticosteroids

During treatment it is likely you will be given drugs called corticosteroids or steroids. Common steroids are prednisolone and dexamethasone.

They can be given as a tablet and/or intravenously (IV). They can help:

- Some chemo destroy cancer cells
- Prevent/treat nausea and vomiting
- Reduce the risk of allergic reaction to some chemo drugs

Difficulty sleeping

Take in the morning after breakfast.

Upset stomach

Take with food or milk.

High blood sugar levels

Diabetics should increase checks and talk to their treatment team about adjusting insulin.

Mood changes

Ask your treatment team to refer you to a counsellor.

Increased appetite and weight gain

Ask your treatment team to refer you to a dietitian.

Swelling due to retaining fluid

Keep an eye on swelling and let your treatment team know if it gets worse.

Targeted therapy

Targeted therapies directly target the mutations/changes inside the blood cancer cells. They also slow down the growth or speed up the rate at which the blood cancer cells die. These treatments cause less damage to normal cells than chemo. Targeted therapies may be given by themselves or given with chemo. Targeted therapies are used in highly specific circumstances and are expensive. In some cases they may only be available on a clinical trial. These treatments are complex, and your doctor will discuss the best options available for you.

Side effects from targeted therapies tend to be different to chemo side effects. If you're having more than one type of drug, you may have a few different side effects at different times. Your treatment team will talk to you about what you might expect.

Immunotherapies

Immunotherapy is sometimes called biologic therapy. It is a type of cancer treatment that uses part of your immune system to fight blood cancer cells. Immunotherapy may be given orally or intravenously. Immunotherapy is often combined with chemo. Side effects from immunotherapies tend to be different from chemo side effects.

Some common immunotherapy side effects include:

- Eye inflammation, causing dry, irritated eyes
- Joint pain
- Dermatitis, causing skin rashes and itching
- Tiredness
- Weight loss or weight gain
- Diarrhoea, abdominal pain and bloating

Your treatment team will talk to you about what to expect.

Monoclonal antibodies

Monoclonal antibodies are a type of immunotherapy. They work by attaching to specific cancer cells to tell your immune system to destroy those cells. They also slow down cancer cell growth. Monoclonal antibodies may be given to people who are not suited to some chemo treatment due to its side effects. These may be given in combination with either chemotherapy or other targeted therapies. Side effects from monoclonal antibodies tend to be different to chemo side effects. If you're having more than one type of drug, you may have a few different side effects at different times. Your treatment team will talk to you about what you might expect.

You can find more information about active treatment options on our [website](#).



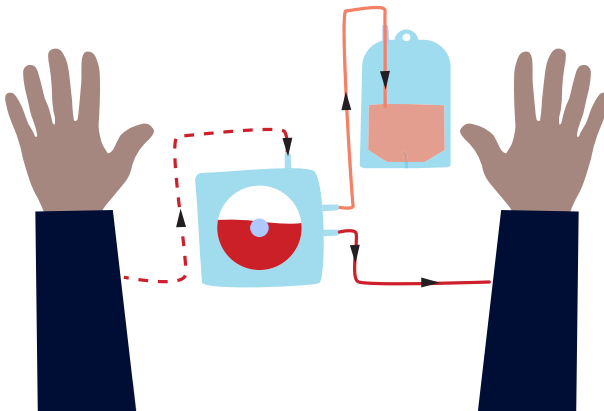
Stem cell transplantation

A stem cell transplant is where your stem cells are replaced with new stem cells after high dose chemotherapy and/or radiotherapy. The aim is to destroy the stem cells in your bone marrow and any disease in your body. The stem cells are then replaced with healthy stem cells. Stem cell transplant, bone marrow transplant and haemopoietic cell transplant (HCT) describe the same process.

A stem cell transplant may be used if the blood cancer gets worse or does not respond to treatment, or the type of blood cancer is known to recur. This treatment is not available for everyone because there are very serious side effects, including a risk of dying.

Autologous stem cell transplant

Autologous stem cell transplants are generally used for lymphoma. In an autologous stem cell transplant your own stem cells are collected when there is minimal disease. The stem cells are collected through either a peripheral blood stem cell collection using an apheresis machine or from the bone marrow. The stem cells are stored and returned to you after receiving high dose chemotherapy. The stem cells travel to the bone marrow and begin to rebuild your blood and immune system.



Apheresis machine

Allogeneic (donor) stem cell transplant

The stem cells transplanted in an allogeneic transplant are from a donor. Usually, a brother or sister with the same tissue type as you. A blood test can see if they are the same tissue type, a HLA matched donor. The stem cells can also come from a volunteer donor who is not related but are a HLA match.

In an allogeneic stem cell transplant the donated stem cells create a new immune system. The new immune system destroys any blood cancer cells left after the high dose chemo. The healthy donated stem cells also rebuild your blood.

Stem cell transplant side effects include:

- Low blood counts.
- All the same side effects as chemo, but more severe.
- Graft-versus-host disease (GvHD) for allogeneic transplants, where the new immune system attacks normal cells.

These side effects can go on for years after the stem cell transplant.

You can find more information about GvHD on our [website](#).



You can find out more about stem cell transplants in our booklets '[Autologous stem cell transplants](#)' and '[Allogeneic stem cell transplants](#)' and on our [website](#).



Autologous stem cell transplants booklet



Stem cell transplants



Allogeneic stem cell transplants booklet

Chimeric Antigen Receptor (CAR) T-cell therapy

CAR T-cell therapy is a type of immunotherapy and gene therapy. It involves changing the genetic make-up of some of your own normal T-cells (immune cells). This is so they recognise proteins on the surface of lymphoma cells and attempt to kill them. T-cells are taken from the blood using the procedure called apheresis. Apheresis is used to collect normal T-cells from the blood which are then sent off to a specialised laboratory to have their genes changed. The genetically modified T-cells have 'chimeric antigen receptors' (CAR) on the surface of the cells. The changed T-cells are called chimeric antigen receptor (CAR) T-cells. They are then given back to the person via IV infusion to kill the cancer cells.

You can find more information about CAR-T Cell Therapy on our [website](#).



Radiation therapy (radiotherapy)

Radiation therapy, also called radiotherapy, is a type of treatment that uses high energy X-rays to kill cancer cells. Radiotherapy is a local therapy because it only destroys cancer cells in the area it treats.

Radiotherapy can be used in to treat single areas of NHL. Radiotherapy is also used to 'consolidate' chemo-immunotherapy, at a site of 'bulk' or extra nodal site.

Some people with NHL affecting the central nervous system may have radiation therapy depending on where they have tumours. Usually, intrathecal chemo is tried first.

Before you start

You will meet with the radiation oncologist (specialist in treating people with radiotherapy), treatment options and goals will be discussed, and you may have a physical examination. Next you'll have a simulation session. This will scan and position you for your radiotherapy treatments. Using these scans your dose of radiation will be calculated. You may have a dot tattooed on your skin, this helps guide treatment.

During treatment

Treatment is usually 15-30 minutes per treatment. Most of this time the treatment team will be setting you up for treatment. Once set up you will be alone in the treatment room. Your treatment team will be able to hear and see you. If you feel nervous you might like to bring along some music.

Any important structures like your heart and lungs will be shielded, so they are not affected by the treatment. You will be positioned like you were at simulation. The radiation machine moves around you to deliver the treatment and makes a buzzing sound. The radiation beam is only on for a couple of minutes. It is important to stay still throughout the treatment. You do not see or feel anything during the treatment and it is painless. You may have short, one or two treatments, or a longer course of radiotherapy. Longer courses are usually given in small doses, called fractions. Treatments are usually weekdays, Monday to Friday, over several weeks.

Side effects

Radiation therapy side effects vary from person to person and are dependent on the area treated. Some are short term, and some can last beyond treatment.

Side effects include:

- Fatigue – extreme tiredness not relieved by rest. You can read more about it on page 55.
- Skin changes – your skin may become red, dry, warm or sore where you are treated. Stay out of the sun. Skin changes will be worst just after your treatment ends. They will usually start to heal four to six weeks after you finish radiotherapy.
- Mouth pain or soreness.
- Feeling sick (nausea and/or vomiting).
- Bowel changes – wind, diarrhoea, bloating, cramping.
- Hair loss – only in the area where you're having radiation.

Radiotherapy follow up

After your course of radiotherapy finishes, you may have scans. Then you'll see your radiation oncologist to discuss how your treatment went.

Surgery

You will have day surgery to have a central line or a port inserted. Surgery may be required to obtain biopsies for diagnostic purposes.

Clinical trials

Clinical trials, or research studies, test new treatments. Your haematologist may suggest you join a clinical trial. Results from clinical trials compare new or combination therapy to current treatments. Results also report any side effects of the new treatment. Many clinical trials are randomised. This means some patients receive the new treatment and others the current treatment. Clinical trials provide important information about how treatments can be improved. In Australia some clinical trials may provide access to expensive new treatments not available on the Pharmaceutical Benefits Scheme (PBS).

For a clinical trial you will need to:

Understand the risks and benefits of the trial.

Understand how your treatment will be different compared to current treatment.

Ask any questions you have before deciding whether to participate in the trial.

Give your informed consent to participate in the clinical trial.

Clinical trials are run through hospitals and clinics. A clinical trial nurse will be part of your treatment team.

Clinical trial participation is purely voluntary.

You can search current clinical trials at the following websites.

Australian Cancer Trials: australiancancertrials.gov.au

ANZ Clinical Trials Registry: anzctr.org.au

ClinTrial Refer: clintrialrefer.org



Complementary therapies

Complementary and alternative medicines are not standard medical treatments. Some people find that they help with side effects and symptoms. No complementary or alternative treatment on its own can treat blood cancer. Tell your treatment team what complementary or alternative medicines you plan to take.

To find out more, visit [Cancer Australia](#).



“Meditate” and “Use breathing techniques.”

Top tips from people with blood cancer

Visit [A mindful moment](#) to ground and calm yourself.



Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue (CRF). It can be hard to describe to people who haven't felt it. It's more than being tired, it's different to normal everyday tiredness, and is often not resolved with sleep or rest. You will feel tired, but you may also feel weak and be sleepy, drowsy, impatient or confused. It's hard when you have no get-up-and-go, however, for most people fatigue should improve after you finish treatment.

"Cancer-related fatigue (CRF) is not the same as being tired."

Top tips from people with blood cancer

Tips for managing fatigue

Fatigue is a side effect of your blood cancer or treatment. Managing fatigue is an important part of your overall treatment and care. Make sure you talk to your treatment team about it, they may suggest a referral to a psychologist who specialises in sleep management. It's particularly important to explain how you feel to your carers and support people. You will need to let them know your priorities and discuss how they can help.

Tips to manage fatigue include:

Napping if tired during the day for up to an hour

Positive sleep routine

Eating well

Drinking plenty of water

Regular moderate exercise or movement

Pre-sleep relaxation techniques

Avoiding use of electronic equipment, such as computers late at night

“Recognise your limits, physical/cognitive/
emotional/social.”

Top tips from people with blood cancer

While you're managing your fatigue, you can jot down what time of day you have most energy and when you feel most tired. That will help you get into a routine and prioritise your energy. Play games, listen to, or play music, read, catch up with friends and family. These things might seem difficult, but they will help distract you from the fatigue.

“Know when you are at your most productive
and do important tasks then.”

Top tips from people with blood cancer

Go to our online [‘Cancer related fatigue’](#) learn module or website to find out more.



Fertility decisions

Some types of treatment may affect your fertility, which is your ability to conceive a baby. It is important to talk to your treatment team about future fertility before you start treatment. If you are planning on having a child, there are steps you can take.

Make sure you understand:

- The fertility preservation processes
- The risks and side effects of fertility treatments
- Success rates
- Any costs involved

The impact of all of these factors vary to the individual so be sure to find the right information and advice for you.

For men

Chemo can stop or lower your sperm production. It can reduce your sperm's ability to move. This can be temporary or permanent. It also affects the hormone testosterone.

The best way to preserve your fertility before treatment is by freezing a semen sample, which contains sperm. This is called sperm cryopreservation.

For women

Chemo can reduce your number of available eggs (ova) and can affect your hormones.

There are several fertility cryopreservation (freezing) options for women. Egg and embryo freezing are common, less so ovarian tissue freezing. For some young women and their families, it may not be possible to pursue fertility options prior to cancer treatment.

Having the opportunity for discussion about your future fertility is important.



Fertility Society of Australia: fertilitysociety.com.au

Practical matters

Navigating the health system

The Australian health system may seem large, complicated and stressful especially when you are also living with a blood cancer. Knowing a bit about how our health system works and who are key people in your care can make navigating the system much easier.

Key people in your health team

Haematologist – A specialist doctor trained in diseases of the blood including blood cancer who leads a team of doctors in your care.

Radiation oncologist – A doctor who specialises in treating cancer using radiotherapy.

Cancer care coordinator (CCC)/Cancer nurse consultant (CNC) – Specialist cancer nurses who coordinate patient care and provide referrals to allied health professionals if needed.

Cancer nurse – A nurse in an outpatient clinic or cancer ward who supports, educates and gives you your chemo treatment.

Occupational therapist – A health professional who helps maintain or improve your quality of life using different techniques and equipment. Occupational Therapists help develop, recover, improve and/or maintain the skills needed for daily living, community participation and vocational pursuits.

Palliative care physician – A doctor who specialises in controlling symptoms and improving quality of life in people with terminal illnesses and chronic health conditions.

Pharmacist – A health professional who prepares, dispenses medicines (drugs), and support your understanding of how to manage your side effects with medication prescribed.

Accredited practising dietitian – A university-qualified professional with ongoing training and education who helps to support your recovery and manage challenges in your diet. Dietitians provide you with personal support to help with your health and wellbeing. They provide expert nutrition and dietary advice, advice to understand how to improve your nutritional health, and help to understand how nutrition affects the body.

Social worker – A health professional who specialises in emotional support, counselling, and advice about practical and financial matters.

Physiotherapist/Exercise physiologist – A health professional who specialises in treating and rehabilitating patients through physical means.

Psychologist – A health professional who specialises in providing emotional support and difficulties such as anxiety, distress, and depression.

Record your important contact details

	Contact name	Phone number and/or email	Comments
Emergency			
GP			
Haematologist			
CNC/CCC			
Chemo day unit			
Pharmacist			
Dietitian			
Social worker			
Psychologist			
Occupational therapist			
Physiotherapist			

You can find out more about navigating the healthcare system as a cancer patient and the wide range of health professionals [here](#).



The new normal – what is it?

Life is not the same as it was before a blood cancer diagnosis. Frequent appointments and regular follow up can be tiring and stressful. Everyday life changes for you and the people around you. Things that were once important don't matter as much. Things that weren't important before now take greater priority.

In essence, a 'new normal' is about living with your blood cancer, creating and maintaining as good a life as possible. Changes you may face include:

- Physical/mental/spiritual
- Emotional/relationships/identity/sexuality
- Financial, ability to work/return to productivity

It is important to seek information and support. Accepting help to manage challenges that arise throughout your cancer experience isn't always easy. Having this support can enable you to have a high quality of life while living with a blood cancer. It is also important to remember that dealing with the diagnosis and treatment of blood cancer is a big life change and everyone handles it differently.

You can find out more about living well with blood cancer on our [website](#).



Go to our online learn module, ['Transition to a new normal'](#) to learn more.



Body image

You may not always look like a patient with cancer. Your physical appearance may improve. In the meantime, do things that make you feel good about yourself. This might include enjoying time with friends, regular exercise and relaxing.

Look Good...Feel Better is a free community service for people with cancer. The program focuses on how to manage the appearance related side effects of cancer treatment. You can visit their website lgfb.org.au or call **1800 650 960**.

Diet and nutrition

Being underweight or malnourished can have a negative effect on your quality of life. Poor appetite and weight loss are associated with symptoms such as weakness, fatigue, pain, and difficulty sleeping.

A high-energy diet is encouraged to meet the changing metabolic demands of your body. During chemo treatment you may experience complications that affect your nutrition. You may take drugs called corticosteroids, as part of your treatment. Steroids can cause weight gain through increased appetite stimulation and fluid retention (oedema).

General nutrition recommendations for people receiving cancer treatment:

Maintain a healthy weight. For many people, this means avoiding weight loss by getting enough calories every day. For people who are obese, this may mean losing weight, get advice from your treatment team.

Get essential nutrients. These include protein, carbohydrates, fats, vitamins, minerals and water.

You can make an appointment to see a hospital dietitian as an outpatient or ask to see one if you are an inpatient. Your treatment team may refer you to a dietitian. Community dietitians are also available. Your GP can arrange this through a care plan if your private health insurance doesn't cover it.



You can find more information about eating well on our [website](#).



“Eat well” and “Use a meal service to stay nourished without having to cook each day.”

Top tips from people with blood cancer

“Need to practise and build up skills over time – multi-tasking/moving/travel/work.”

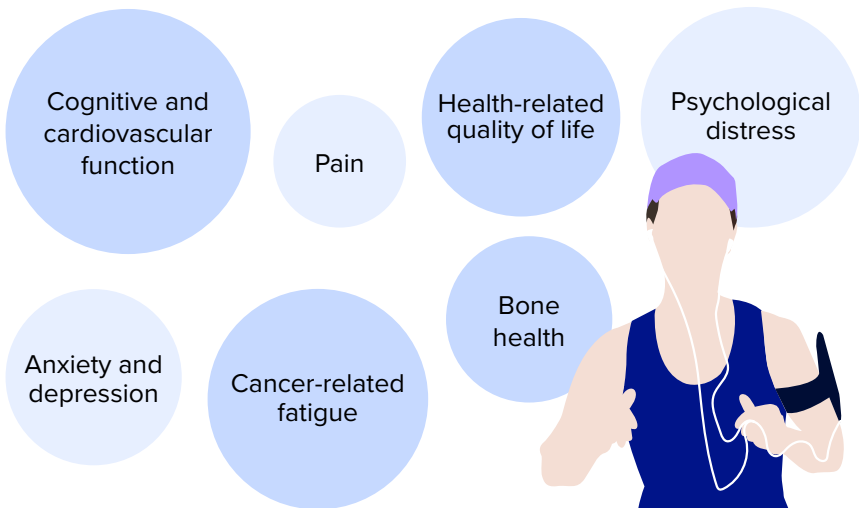
Top tips from people with blood cancer

Physical activity

It is common to experience a physical and/or psychological drop in function. This is called deconditioning. Having cancer doesn't mean you can't be physically active. Avoid inactivity and sedentary behaviour as much as possible.

What are the benefits of exercise/physical activity?

Strong evidence has shown that exercise and physical activity improves outcomes for people with cancer for:



“Doing something is better than nothing”

Top tips from people with blood cancer

Exercise can be tailored to the individual around activities of daily living. Before you start an exercise program speak with your treatment team. Check to make sure it is safe to do so and to see who is best placed to help you.

Information on exercise with cancer can be found on the Clinical Oncology Society of Australia (COSA) website: cosa.org.au

Specific information for older people on exercising with chronic illness and some advice about healthy eating is available from the Australian Government. [Choose Health, Be Active – a physical activity guide for older Australians.](#)



Mental health and emotional wellbeing

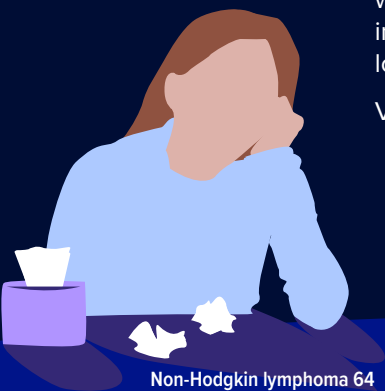
Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings. It is not uncommon to feel low, depressed, or anxious. Feeling sad is a normal response to a cancer diagnosis as is worrying about the future. **Feelings can be challenging and may include:**

- Anxiety
- Grief
- Guilt
- Uncertainty
- Anger
- Spiritual distress
- Fear
- Feeling isolated or lonely

Worrying about treatment, its success and side effects can impact your mental health. Changes in your physical, lifestyle, and family dynamics can also impact your wellbeing. Seeking help from your treatment team is important. They and/or your GP can refer you to someone who can help, such as a **psychologist who specialises in blood cancer.**

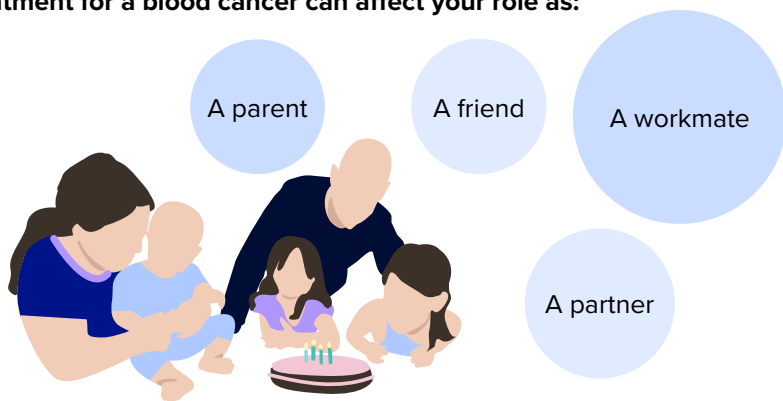
The Leukaemia Foundation's Blood Cancer Support Coordinators can also help you to work through what you are feeling and provide information on who might assist you in your local area.

Visit leukaemia.org.au or call **1800 620 420.**



Relationships, carers, family and friends

Treatment for a blood cancer can affect your role as:



You and the people in your life will cope in different ways. Encourage open communication between yourself, family and friends. Effective communication with family, children, friends, and carers is essential. Being clear with others about what you want and need allows them to be of greater support. Together you can work as a team to manage and solve problems as they arise. There are resources and other organisations that can assist with support and information.

The Leukaemia Foundation's Blood cancer support coordinators can assist you, your carer or family in identifying who can help with different issues and how to contact them (1800 620 420 or support@leukaemia.org.au).

For information for carers go to our online '[Carers](#)' learn module.



Carers Australia: carersaustralia.com.au

Carer Gateway (Australian Government): carergateway.gov.au

Canteen: canteen.org.au

Redkite: redkite.org.au

Relationships Australia: relationships.org.au

Sexuality and sexual activity

It is likely the experience of the treatment will have some impact on how you feel about yourself. Hair loss, skin changes, weight gain or weight loss and fatigue can all interfere with feeling attractive. You may experience a decrease in libido, which is your body's sexual urge or desire. It may take some time for things to return to 'normal'. It is safe to have sex as soon as you feel like it, but there are some precautions you need to take. It is usually recommended that you or your partner do not become pregnant for some time after treatment. Some of the treatments given can harm the developing baby. You will need to use a suitable form of contraception. Condoms (with a spermicidal gel) provide good contraceptive protection. This also protects against infection or irritation.

Always use barrier protection/condoms to protect your partner if you are having chemotherapy or immunotherapy.

Partners are sometimes afraid that sex might harm the patient. This is unlikely, as long as the partner is free from infections and the sex is gentle. This is especially important if your platelet count is low. If you experience vaginal dryness and irritation the use of lubricants is helpful.

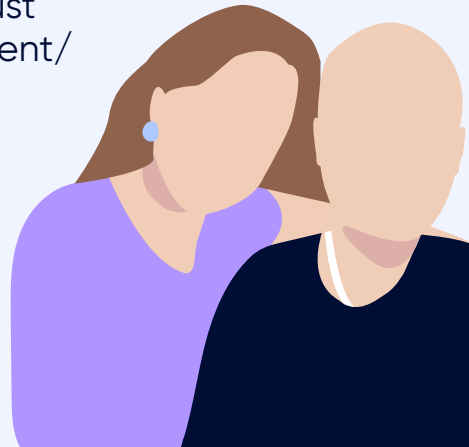
If you have questions or concerns about sexual activity and contraception talk to your treatment team. You may ask for a referral to a doctor or health professional who specialises in sexuality.

Find out more about sexual health during and after a blood cancer diagnosis [here](#).



“Pay attention to emotional fatigue in relationships – adjust expectation/social commitment/hours of care given”

Top tips from people with blood cancer



Work, finances and legal matters

Finances

People with blood cancer often report a negative impact on their financial situation during treatment. Monthly costs can increase for items such as travel, childcare and, taking time off work for appointments. Your household income may reduce due to you or your carer having to stop work, or reduce hours permanently or temporarily.

A financial stocktake

A good first step is to run a quick 'financial stocktake'. First, assess what income you can expect or what financial resources you have available.

Possibilities may include:

Are you or your partner able to work part-time?

Do you have sick leave or long service leave?

Do you have income protection or trauma insurance, either as a stand-alone policy or part of a life insurance policy, or through a superannuation policy?

Do you have money in the bank or a line of credit against your mortgage which you can access?

The second step is to check on important expenses which need paying in the immediate future. Put together a brief budget if you don't have one.



To find out more visit our [website](#)



Seeking help

Financial advice around budgeting and what financial assistance is available to you can be discussed with a number of sources.

The Leukaemia Foundation's Blood cancer support coordinators can help point you in the right direction (1800 620 420 or support@leukaemia.org.au).

A few key other options to consider are:

Centrelink

If you expect your income to reduce, the first organisation to contact is Centrelink. The earlier you make an application, the sooner you could receive relief payments. If you have employment to return to, this will affect the basis of your benefit. Your partner may also be eligible for a Carer Payment or Carer Allowance, so be sure to enquire about this.

Centrelink online account (sign in through myGov for instructions): centrelink.gov.au

Financial institutions

It is important that you let organisations know as soon as possible if you think you will have financial difficulties. Banks and other financial organisations have special arrangements for customers in financial hardship because of ill health.

Other sources of help

Discuss your financial circumstances with a social worker or your private insurer. They may be able to assist with advice on deferring payments.

- Many providers have hardship support programs (like energy providers).
- State governments have hardship programs available.
- It may be possible to access some money from your superannuation fund to help with emergency payments.

Don't forget to check if your superannuation has income replacement insurance. If you are not sure, give their helpline a call.

To find out more go to:

Money smart: moneysmart.gov.au

National Debt Helpline: ndh.org.au or phone **1800 007 007**

Getting back to work

The decision about when to return to work is a very personal one. It will depend on how well you are feeling, the type of work you do, and your personal and financial circumstances.

On return to work some people may go back part-time, increasing their hours when they feel up to it. Discuss timeframes for returning to work with your doctor.

“Make a plan with your workplace”

Top tips from people with blood cancer

Find out more about returning to work or study on our [website](#).



Discover more on our online learn module, [‘Return to work.’](#)

Legal matters

This information applies to all members of the community, not just those who have a blood cancer or their carer. The best time to get your affairs in order is when you are in good health. Here are some of the most common legal documents you should have and where to get help.

Enduring Power of Attorney/Enduring Guardian

There may be circumstances when a person loses the capacity to make decisions. You can sign a legal document which allows you to choose a trusted person to make decisions on your behalf.

An Enduring Power of Attorney (EPOA) is a document that allows your trusted person the power to sign documents on your behalf. They also can make personal and administrative decisions, and if you choose, financial decisions.

An Enduring Guardian (EG) is a trusted person who can make decisions on your behalf regarding your health including medical treatment, care and protection (even if this decision is against your wishes). An Enduring Guardian (EG) requires another legal document. **To find out more visit the Australian Guardianship and Administration Council at agac.org.au**

Wills

It is very important to have specialist legal advice when preparing your Will. Intestacy is the condition of your estate if you die without a valid Will. Intestacy laws set out the way in which an estate will be distributed when there's no Will. This process is very specific and may not reflect your personal wishes. You will need to determine who will be responsible for your dependents in the event of your death. Even if your affairs are very simple and your immediate family will receive your assets, you need a Will. If you already have a Will, you need to consider if it is still current.

Advance Health Directive

This is a document that states your wishes about medical treatments. It indicates those you may or may not wish to receive in the event of a serious illness or accident. Although lengthy, it is simple to complete as it consists of a series of optional questions. There are also sections where you make comments in your own words. While this form can be completed on your own, you may wish to discuss it with your family. A doctor must sign the form to certify that you understand the contents of the document.

Advance Care Planning Australia: advancecareplanning.org.au or phone 1300 208 582.

Getting help

Help with legal matters is available from several sources including solicitors, trustee companies, the Public Trustee in your state, and the Australian Guardianship and Administration Council.

To find out more about putting your personal affairs in order, visit our [website](#).



And our online learn module, '[Financial and legal matters](#).'

**More
information
and help**

Glossary

You can find any **bold** terms in the definitions also defined in this glossary.

Anaemia – a lower-than-normal number of red blood cells in the blood. It causes tiredness, paleness and sometimes shortness of breath.

Baseline – a first measurement of a condition taken early on, used to compare over time, to look for changes.

Blast cells – immature blood cells normally in the bone marrow in small numbers.

Bone marrow – soft, sponge-like tissue in the centre of most bones. It contains stem cells that make all blood cells.

Bone marrow biopsy – also called a bone marrow aspirate and trephine or BMAT. The removal of a small sample of bone marrow. This is sent to the lab for a pathologist to look at under a microscope.

Biotherapy – a type of treatment that uses substances made from living organisms to treat disease. These substances may occur naturally in the body or may be made in the laboratory.

Bone marrow aspirate – a procedure that takes a sample of bone marrow fluid.

Bone marrow transplant – also called a stem cell transplant. A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).

Bone marrow trephine – a sample of bone marrow tissue.

Cancer – diseases where some of the body's cells become faulty, begin to multiply out of control, can invade and damage the area around them, and can also spread to other parts of the body to cause further damage.

Chemotherapy – the use of drugs to treat cancer.

Chromosome – part of a cell that contains genetic information.

Coagulation – process of changing from a liquid blood to a solid. Also called clotting. Platelets help with coagulation.

Cytogenetic tests – the study of the structure of chromosomes. These tests are carried out on samples of blood and bone marrow. The results help with diagnosis and getting the most appropriate treatment.

Cytopenia – where there is a lower-than-normal number of a type of blood cell in the blood.

Dysplasia – also called dysplastic cells. A change in size, shape and arrangement of normal cells seen under a microscope.

Erythrocytes – also called red blood cells. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.

Full blood count – also called FBC or complete blood count. A routine blood test that measures the number and type of cells, and the haemoglobin and haematocrit in the blood.

Growth factors – proteins that control cell division and cell survival. Some are made in the lab and used as treatments, such as G-CSF.

Haematocrit – the amount of blood that is made up of red blood cells.

Haematologist – A doctor who specialises in diagnosing and treating blood disorders.

Haemoglobin – a protein inside red blood cells that carries oxygen around the body.

Haemopoiesis – the formation of new blood cells.

Immune system – the body's defence system against infection and disease.

Immunotherapy – sometimes called biological therapy, is a type of cancer treatment that works by boosting a person's own immune system to fight the cancer.

Leukocytes – also called white blood cells that are made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system. Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

Megakaryocytes – very large bone marrow cells that break apart to form platelets.

Mutation – A harmful change in 'normal' DNA (the building blocks of all cells).

Neutropenia – a lower-than-normal number of neutrophils in the blood. It increases the risk of infection.

Neutrophils – the most common type of white blood cell. They help fight infection.

Pancytopenia – where there are lower-than-normal numbers of a type of all blood cells and platelets in the blood.

Pathology – the study of diseases to understand their nature and their cause. A specialist in this field is called a pathologist. In cancer, histopathology/histology involves examining tissue under a microscope. Haematopathology involves blood and lymph tissue.

Petechiae – tiny, unraised, round red spots under the skin caused by bleeding.

Platelets – also called thrombocytes. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.

Prognosis – an estimate of the likely course and outcome of a disease.

Purpura – bleeding and bruising under the skin.

Radiotherapy (radiation therapy) – uses high-energy radiation from X-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells or injure them so they can't grow or multiply.

Red blood cell – also called an erythrocyte or RBC. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.

Relapse – return of the original disease after it has improved for a time.

Remission – where the signs and symptoms of cancer decrease or disappear. Remission can be partial (a reduction in some or many symptoms) or complete (all symptoms have disappeared). Remission is not the same as a cure. Even in complete remission cancer cells may still be in the body.

Rigor – also called a chill. Feeling cold with shivering or shaking and looking pale, but with a high temperature. A symptom of infection.

Stem cells – young (immature) blood cells that can develop into more than one type of cell. Bone marrow stem cells grow and produce red blood cells, white blood cells and platelets.

Stem cell transplant – also called a SCT or bone marrow transplant. A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).

Thrombocytes – also called platelets. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.

Thrombocytopenia – a lower-than-normal number of platelets in the blood. It causes bruising and bleeding.

White blood cells – also called leukocytes or WBCs. Blood cells made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system. Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

Useful websites



[Leukaemia Foundation](#)



[Australian Cancer Trials](#)



[eviQ Cancer Treatments Online](#)



[Pharmaceutical Benefits Scheme](#)



[Lymphoma Australia](#)



[ClinTrial Refer](#)

Question builder

Who will be my main contacts?

How do I best contact them?

What can I do to avoid infections?

Can I have a flu shot and other vaccinations?

Is it safe to take my supplements and/or vitamins?

Can I eat normally?

Is there anything I need to avoid or special diets that will help me?

Can I exercise and what is the best frequency and type for me?

Are there any clinical trials for my type of NHL and am I eligible?

Could this treatment affect my sex life?

If so, how and for how long?

Will my treatment send me into menopause?

Where can I or my loved ones get any other support?

The Leukaemia Foundation gratefully acknowledges those who assisted in the development of this information: Leukaemia Foundation Blood Cancer Support Coordinators, nursing staff, clinical haematologists, and bone marrow transplant physicians representing the various states and territories of Australia.

The Leukaemia Foundation values feedback. If you would like to make suggestions or tell us about your experience in using this booklet, please contact us.

Email: info@leukaemia.org.au

Phone: 1800 620 420

