# Non-Hodgkin Lymphoma (NHL)

A guide for people with NHL and their support people

Leukaemia Foundation®

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

We know you may be feeling anxious or overwhelmed if you or someone you care for has recently been diagnosed with NHL. Maybe you are discussing different treatment options with your treatment team or maybe you have started treatment. Whatever point you are at, this booklet will answer some of your questions and it may raise others, which you can jot down and discuss with your haematologist or nurse.

If you don’t feel like reading this booklet from cover to cover, take a look at the Contents list and choose which parts to read now. You can come back to read other parts later on. You may need more information, and it is important to be careful that you obtain this information from reliable sources so towards the back of the booklet there is a list of useful resources. Your doctor or nurse might also give you some further reading. You can always call our Blood Cancer Support Coordinators to find out how we can help you.

You will meet many different types of healthcare professionals who work as a team to provide you with the best treatment available. The people you will see most often will be haematologists and haematology nurses, and you'll need a regular GP, but you'll also meet pathologists and allied health professionals, like dietitians. In this booklet, when we refer to 'your treatment team’ we usually mean your haematologist and haematology nurses.

You will come across quite a few medical terms in this booklet. They are words that your treatment team will probably use and that you may not have heard before. Your treatment team will be happy to explain any terms you don’t understand, so never be afraid to ask. Many of these words are defined in the text or in the Glossary at the end of this booklet.

Although we provide some information about treatments, this booklet does not recommend any particular form of treatment and you must discuss your circumstances and best treatment options with your haematologist.

We hope you find this information useful. We’d love to hear any feedback so we can make sure we best meet your information needs.

*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.*

# Contents

# 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, and enlarged organs, like the spleen.

NHL is diagnosed using blood tests, a lymph node biopsy, scans, and a bone marrow biopsy.

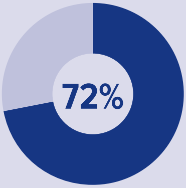
Treatment includes observation, chemotherapy, immunotherapy, and radiotherapy. Some people have stem cell transplants. As the treatments for NHL are rapidly developing, new treatments may be delivered as part of a clinical trial.

In most cases, we don't know what causes NHL. There are usually one or more *mutations* in (changes to) the genetic material or 'DNA' 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.

Scan to learn more about how the Leukaemia Foundation can provide you with additional support and the latest information about your blood cancer.

## Who gets NHL

**5031**
Australians diagnosed each year



72% of people diagnosed aged >60

**67**
average age of diagnosis

Risk of diagnosis 75YO

♀ 1 in 88
♂ 1 in 50

Risk of diagnosis 85YO

♀ 1 in 63
♂ 1 in 35

## What's the prognosis?

A prognosis is an estimate your haematologist will make of the likely course and outcome of your disease. When you are diagnosed, your haematologist may use a 'prognosis calculator' like the International Prognostic Index.

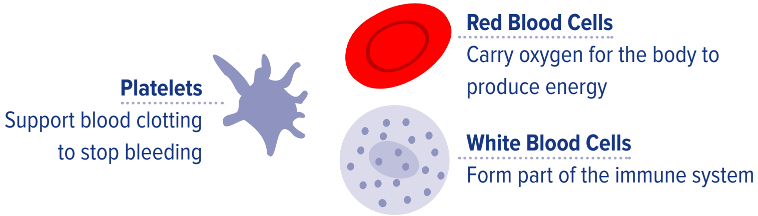
Your haematologist will take into account many factors when considering your prognosis. Some of these are the subtype of NHL you have, its stage, the number and location of lymph nodes affected, your age, and your overall health. It is important to remember that average prognoses are generalised from large numbers of patients with similar characteristics and so only have a limited ability to predict outcomes for an individual patient.

# All about blood

## What is blood?

Blood travels to all parts of the body, carrying oxygen and nutrients and removing 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. 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 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.

### White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs.

Although they make up only a small part (1%) of the blood, white blood cells protect us against and fight off infection. While all of them are important, you will hear the most about neutrophils and lymphocytes. Neutrophils fight bacteria and are especially important in recovering from chemotherapy.

### Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They help your blood clot or stick together; a process called coagulation. They help stop bleeding when you have an injury.

| Condition | Cause | You might notice |
|---|---|---|
| **Anaemia** | Low RBCs or Hb | Tiredness, weakness, pale skin, shortness of breath, heavy legs |
| **Leukopenia** | Low WBCs | More frequent or severe infections |
| **Thrombocytopenia** | Low platelets | Bruising and bleeding, like nosebleeds |
| **Pancytopenia** | All three types low | A mix of symptoms from all three conditions |

## Where and how is blood made?

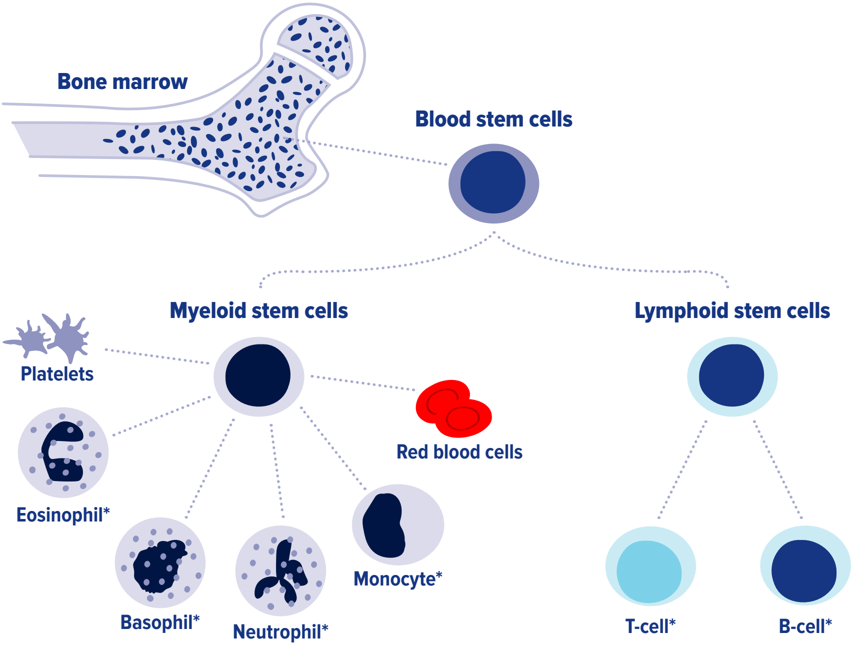
### Bone marrow

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

In children, haematopiesis takes place in the long bones, like the thighbone (femur). In adults, it's mostly in the spine (vertebrae) and 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 as 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: red blood cells for 80-100 days, neutrophils 8-14 days, and platelets 4-5 days. 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.

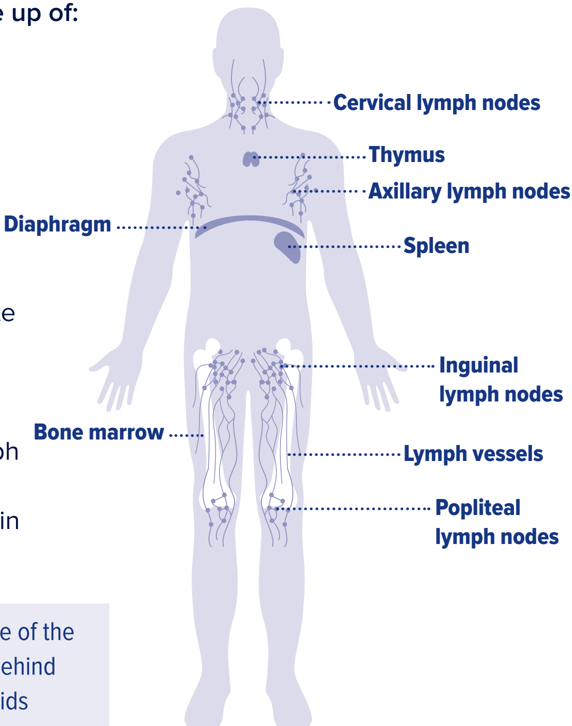
# All about the lymphatic system

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.



The spleen (an organ on the left side of the abdomen), thymus (a gland found behind the breast bone), tonsils and adenoids (glands in the throat), and bone marrow all contain lymphatic tissue and are part of the lymphatic system. These tissues perform similar roles to lymph nodes, but in different parts of the body. There is also lymphatic tissue in the stomach, gut, and skin.

# All about lymphoma

Lymphoma is a group of cancers that develops in the lymphatic system. There are two main types of lymphoma: NHL and Hodgkin lymphoma.

There are more than 80 subtypes of NHL and five subtypes of Hodgkin lymphoma. This is a very important point to realise as your NHL may be very different from someone else's and so your experiences and expectations could be very different. The factors that make up these lymphoma subtypes are defined by the World Health Organization (WHO). Your haematologist will want to make sure the correct subtype is identified as this is one of the most important determinants of prognosis and treatment choice.

# 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, and it might also be in another part of the body where there is lymphatic tissue, such as the spleen, liver or bone marrow. In more 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:**

1. B-cell lymphomas, which affect developing B-cells, and
2. T-cell lymphomas, which affect developing T-cells.

NHL is also described by how fast it grows.

**Indolent lymphomas** (also called *slow-growing* or *low-grade lymphomas*) may grow slowly over many years. People with indolent lymphomas may not have symptoms and may not need treatment when they are diagnosed.

**Aggressive lymphomas** (also called *intermediate-grade* and *high-grade lymphomas*) grow faster, may cause more severe symptoms, and usually need to be treated soon after they are diagnosed.

**Common types of NHL**

| **Slow-growing (indolent/low grade)** | **Aggressive (intermediate/high grade)** |
|---|---|
| Cutaneous T-cell lymphoma (CTCL) | Anaplastic large-cell lymphoma (ALCL) |
| Low grade follicular lymphoma (FL) | Burkitt's lymphoma |
| Marginal zone B-cell lymphoma (MZL) | Diffuse large B-cell lymphoma (DLBCL) |
| Waldenström's macroglobulinaemia (WM) | Lymphoblastic lymphoma |
| Small lymphocytic lymphoma (SLL) | Peripheral T-cell lymphoma |
| Indolent mantle cell lymphoma (iMCL) | Blastic mantle cell lymphoma |
| Mucosa-associated lymphoid tissue (MALT) lymphoma | |

You can read more about subtypes of NHL in our factsheets and 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).

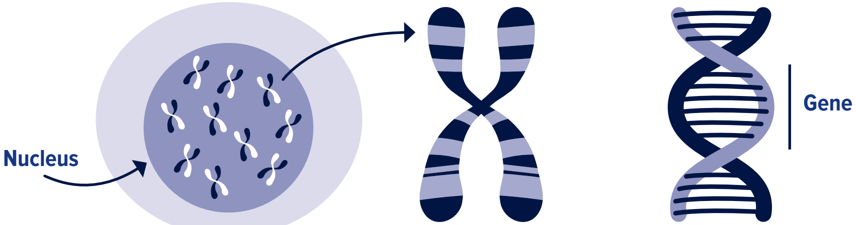
Your haematologist will use the WHO system to work out which subtype you have and the right treatment for you.

# How does NHL develop?

Lymphomas start in developing white blood cells called *lymphocytes* in the lymphatic system. There are three types of lymphocytes: 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. These tumours cause swelling in the lymph nodes and other parts of the body. Over time, cancerous lymphocytes (called *lymphoma cells*) crowd out normal lymphocytes. Eventually, the immune system becomes weak and it can’t function properly. Lymphocytes may also crowd the bone marrow, which means not enough normal blood cells can be made.

Inside cells there are coded instructions that control how the cell should act. Chromosomes inside cells are long strands of DNA (deoxyribonucleic acid). 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. But some things (*risk factors*) give some people a higher risk of developing NHL, including changes to the immune system.

## Known risk factors

- Sometimes viruses, such as **Epstein-Barr virus**, which causes glandular fever, or the T-cell lymphotropic virus (HTLV-1) can increase risk of developing lymphoma.
- A **weak immune system**, and conditions like HIV or drugs used to suppress immunity after organ transplant, may weaken immunity.
- **Autoimmune diseases**, such as rheumatoid arthritis (RA), systemic lupus erythematosus (SLE) or Sjogren disease.
- A few **long-term infections** are associated with types of MALT lymphoma: *Helicobacter pylori, Chlamydophila psittaci*, and *Campylobacter jejuni*.
- Exposure to high levels of some environmental **chemicals**, especially benzene and petroleum products.
- Having a close **family member** (parent or sibling) with NHL.
- People treated in the past for cancer with certain kinds of **chemotherapy**.
- Previous **radiation therapy**, or accidental exposure to high levels of **environmental irradiation**.
- Rarely, some women with some older type **breast implants** can develop breast implant associated T-cell lymphoma.
- 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.

**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 in deeper parts of the body. **If you have it in:**

- the belly (abdomen); you may have gut pain or a feeling of swelling
- the spleen; you may have abdominal pain and a feeling of fullness 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 too. These are 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 located in the top left of your belly, near your rib cage. When the spleen is swollen (enlarged), it is called splenomegaly. If you have splenomegaly, you may feel fullness, discomfort or pain in the upper left side of your abdomen and you may rapidly feel full when eating.

Your liver can act in the same way. When the liver swells up, it's called *hepatomegaly*. It will feel similar to splenomegaly, but is in the top right of your belly.

## Low blood counts

Many symptoms of NHL are a result of blood cell counts below the normal range. Your bone marrow can't make enough healthy cells. You may have lower-than-normal numbers of red blood cells, white blood cells or platelets, or a combination of these if the lymphoma cells are crowding your bone marrow.

Anaemia is caused by low red blood cells. Red blood cells are important for carrying oxygen around your body.

You may have a low number of a type of white blood cells called neutrophils. This is called *neutropenia*. White blood cells are necessary to support your immunity.

*Thrombocytopenia* is a low platelet count. Platelets help control bleeding and help wounds to heal.

You may have symptoms from each of these groups because all your blood cell types can be low (this is called *pancytopenia*).

| Condition | Cause | You might notice |
|---|---|---|
| **Anaemia** | Low RBCs or Hb | Tiredness, weakness, pale skin, shortness of breath, heavy legs, difficulty concentrating, feeling lightheaded, rapid or irregular heartbeat. |

| | | |
|---|---|---|
| **Neutropenia** | Low WBCs (neutrophils) | More frequent or severe infections, e.g. chest or skin, fevers, shivering, chills, low blood pressure, mouth ulcers. |
| **Hypogammaglobulinaemia** | Low gamma globulins | Coughing, sore throat, fever, ear pain, congestion, sinus pain, diarrhoea, nausea and vomiting. |
| **Thrombocytopenia** | Low platelets | Easy bruising and bleeding, e.g. nosebleeds, cuts that keep bleeding, coughing up blood, petechiae – tiny, unraised red blood spots under the skin, often starting on legs. |
| **Pancytopenia** | All three blood cell types are low | A mix of symptoms from all three conditions. |

*Petechiae*

# How is NHL diagnosed?

Your haematologist will diagnose NHL by talking with you about how you are feeling, and looking at samples of your blood and a lymph node biopsy. Some symptoms of NHL, like feeling tired and low or abnormal blood counts, are part of many conditions. You may need a few types of tests before lymphoma is diagnosed.

## Medical history and physical exam

First, your treatment team will take a full medical history. They'll ask you to talk about past and present illnesses, health problems, infections, and bleeding. They'll also need details of any old and new medicines you're taking, including prescribed and any over the counter medications you take regularly.

Your doctor will also do a physical examination, to check your general health and your whole body for any signs of NHL, like swollen glands in your neck, armpits, and groin. Your belly and chest will also be examined for swelling.

## Full blood count

You'll 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 haematopathologist (a 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 are often taken at the same time as your FBC and 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 lymphoma you have and treatments you have received, you may have low or high levels of antibodies. Low antibody levels may predispose to infections.

| Substance tested | What it indicates |
|---|---|
| **Creatinine** | Kidney function |
| **Electrolytes** | Kidney function |

| | |
|---|---|
| **Blood urea nitrogen (BUN)** | Kidney function |
| **Calcium** | Bone destruction |
| **Uric acid** | Cell breakdown |
| **Lactate dehydrogenase (LDH)** | Blood cell damage |
| **Beta-2 microglobulin** | Level of lymphoma in the body |

## Lymph node biopsy

When you have a lymph node biopsy, you will have all or part of a lymph node removed. You'll have the procedure in day surgery or in the imaging (radiology) department of a hospital. You may have a local anaesthetic, gentle sedation or general anaesthetic, depending on how the biopsy is being done.

The core biopsy will take around 30 minutes. An **excisional biopsy** is a minor operation to remove part, or all, of a lymph node and the type of anaesthetic depends on where in the body the lymph node 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 before having sedation or an anaesthetic. You will be able to go home the same day but shouldn't drive, so arrange for transport home.

Your lymph node sample is sent to the lab, where a specialist doctor (pathologist) looks at it under a microscope. A number of other special tests may be performed on the biopsy, including testing for mutations and studying 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 initial biopsy may not provide enough information to accurately diagnose lymphoma or the particular subtype. In these cases, your doctor will organise a repeat biopsy; either from a different site or by taking a larger amount of tissue. It is very important that the biopsy is accurate in order to determine the best course of treatment.

# Disease staging

The stage of your lymphoma shows how the disease is affecting your body. It describes how many and which areas of your body are affected by lymphoma. This helps with treatment planning and determining prognosis.

There are four stages of NHL.

In Stages 1 and 2, lymphoma is limited to one or two areas of the body. This is called *early stage* lymphoma. In 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 lymphoma** | Lymphoma is in lymph nodes above and below the diaphragm* and/or has spread to a nearby organ and/or the spleen. |
| **Stage 4 lymphoma** | Lymphoma has spread widely to one or more organs outside the lymphatic system, for example to the bone marrow, lungs, liver or cerebrospinal fluid (CSF). Lymph nodes close by these organs may or may not be included. |

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

### A, B, E or bulky?

Each stage is described further according to the symptoms you have when you are first diagnosed. If you do not have any symptoms, the letter ‘A’ will appear after the stage of lymphoma, for example, Stage 2A.

If you have symptoms such as fevers, night sweats and unexplained weight loss, the letter ‘B’ will be put after the stage of your lymphoma, for example, Stage 2B.

The letter ‘E’ (for extranodal) is used when 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 an ‘S’.

If you have an area of lymphoma with a large diameter, it is called ‘bulky’. Definitions of ‘bulk’ vary but range from a diameter of 5.5-10cm. In the past the letter ‘X’ was added after the stage number, for example, Stage 3X, to indicate bulky disease.

## Staging tests

### Bone marrow biopsy

If your treatment team thinks you may have NHL in your bone marrow, you’ll have a bone marrow test.

This test is more complex than a blood test, but it won’t involve a hospital stay. It will be done in your haematologist’s rooms or in a day procedure clinic or outpatient ward in a hospital. It’s a good idea to bring a support person with you to keep you company while you wait and to help you home, as you may not be able to drive.

#### *What does a bone marrow biopsy involve?*

A bone marrow biopsy involves using a needle to enter the bone marrow, most commonly in the back of the hip bone. This is an area where the bone is usually quite close to the skin and can be easily accessed by the bone marrow needle. A small amount of liquid bone marrow is usually taken and placed onto slides that are examined in the laboratory. The liquid bone marrow is also sent for additional specialised tests. ***Is a bone marrow biopsy painful?***

Having a bone marrow biopsy is sometimes painful. With the use of local anaesthetic before the bone marrow needle is inserted this pain is usually well tolerated. Often, you will be given a form of pain preventer that you breathe in, or a small dose of sedative (under appropriate hospital conditions) to assist in the management of the discomfort.

### *What to expect after*

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. You may not have any pain but if you do, take a paracetamol tablet. You can take off the dressing and shower 24 hours after the test, or as advised by your treatment team.

You may have to wait a few days for the results of the bone marrow biopsy.

## Cytogenetic tests

Cytogenetic tests on the bone marrow are one type of genetic test. The results give your treatment team information about the genetic make-up of your cells. They look at the structure of chromosomes in bone marrow cells to see if there is any gain, loss or switching of genetic material between chromosomes. Your haematologist will use the results to help work out which type of NHL you have and to plan your treatment.

### *FISH*

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

### *Flow cytometry*

Flow cytometry uses a laser to look for proteins on the surface of a cell. Every type of lymphocyte 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 different types of NHL that look the same under a microscope.

## Molecular genetic tests

Molecular genetic tests, such as polymerase chain reaction (PCR), look directly at the genetic sequence/code and help your haematologist work out the best course of treatment based on any mutations you may have. It may take a few weeks for these test results to come through.

### *PCR*

PCR, sometimes called *quantitative reverse transcriptase* PCR or QPCR, uses DNA to look for specific gene mutations. This test can find one lymphoma cell in more than 100,000 normal cells. It is often done at the same time as cytogenetics/FISH, and it also checks for the BCR-ABL gene. This test is used regularly after treatment starts, to monitor your response.

### *NGS and PCR*

Next generation sequencing (NGS) and PCR uses DNA to look for specific gene mutations. It is often done at the same time as cytogenetics/FISH.

## HLA testing

HLA testing looks for human leukocyte antigen. The test is also called *tissue typing* or *histocompatibility testing*. It tests which HLA genes someone has inherited. Stem cell transplants from a donor ('allogeneic stem cell transplants') are infrequently used as a treatment for lymphoma. If you are potentially eligible for an allogeneic stem cell transplant, then your doctor may test your HLA type. This will be compared to the HLA test of potential donors to see if they are matches. Autologous stem cell transplants (using your own stem cells) are more common for people with NHL and don't require any tissue (HLA) matching. *You can read more about stem cell transplants later in this booklet.*

## Imaging tests

***CT, MRI, or PET scans look for signs of lymphoma in parts of your body, like your spleen and lymph nodes.***

### *CT scans*

CT scans show three-dimensional (3D) images of parts of your body. They can find tiny changes in tissue density (thickness). A CT scan can accurately measure the size of lymph nodes to determine if they are enlarged. While the scan is being done, you lie flat and still on a cushioned table that moves slowly through the CT machine. Sometimes, you may have a special dye (called a *contrast*), which you swallow or which may be injected into a vein in your hand or arm before the scan. The CT scanner shows the contrast as it moves through your body.

### *PET scan*

For a PET scan, glucose that has been 'labelled' by a special radioactive substance is injected into a vein in your hand or arm. Special cameras follow the labelled glucose as it moves through your body and is taken up by any tissues in the body that are particularly active or 'hot' in consuming glucose.

It is normal on a PET scan for the heart and brain to light up because of this increased uptake of glucose, as do lymph nodes that contain lymphoma more so than a normal lymph node. A PET scan helps to stage your lymphoma more accurately than a CT scan alone does. PET scans are also useful for identifying a good lymph node to biopsy. You will have a PET scan during and after treatment, to check how it is going. It is important to remember that a hot lymph node, or other tissue on a PET scan, does not always equate to lymphoma involvement and so always needs to be correlated with symptoms and biopsy results.

### *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.

## Other tests

Some people will have tests that relate to their specific symptoms and subtype. **These tests include:**

- endoscopy, which checks your upper (a gastroscopy) or lower (a colonoscopy) gastrointestinal tract
- a testicular ultrasound for men who have a testicular lump
- a lumbar puncture, to check for lymphoma cells in the fluid that surrounds your brain and spinal cord.

## 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.

**Multidisciplinary team meetings**

Once all your biopsies and staging tests have been completed, your case may be presented at a multidisciplinary team (MDT) meeting. Usually, an MDT meeting will include a number of specialist haematologists, radiologists (X-ray and PET experts), radiation oncologists (radiotherapy experts) and pathologists. The pathologist will review the biopsy to ensure the lymphoma diagnosis and subtype is accurate. In some cases, they may recommend a repeat biopsy is obtained or more special tests are ordered on the existing biopsy. The radiologists will review all the scans to help clarify the stage. With all the information double-checked, the haematologists and radiation oncologists will suggest the best treatment options. This process ensures that initial diagnosis and staging are accurate. Having multiple experts discuss the same case ensures that the most up-to-date recommendations for treatment are put forward. A case may also be re-presented at an MDT meeting during treatment (to ensure treatment responses are adequately monitored) or at a time of suspected lymphoma relapse.

# What happens next?

## After diagnosis

When all your test results have been reviewed, you'll meet with your haematologist to discuss your NHL, the subtype, and your treatment goals and options. It is natural to feel scared, confused or sad. You'll hear a lot of information and it can be overwhelming. In some cases, you may feel relieved and reassured that your symptoms have been explained and may improve significantly following treatment.

Don't be afraid to ask your haematologist to repeat details and for some written information. It's helpful to bring someone along to the appointment, as a second pair of ears and to take notes.

# Intravenous access for treatments

Many lymphoma treatments are given directly into a vein (*intravenously*, or via *IV*). There are two broad ways to provide access to your bloodstream; through the peripheral veins in your arms or through a central vein in your chest. Most people will need both forms of intravenous access throughout their treatment, but some treatments can only be given through a line into a central vein. Your treatment team will discuss them with you before you start treatment so you can understand which is best for you.

### *Peripheral intravenous cannula*

A cannula is a short, thin plastic tube. It has a thin needle that your nurse will put into a vein in your lower arm or the back of your hand. It will be held in place with a dressing. The cannula is connected to the lines that give you your treatment, often through a pump. Having a cannula inserted may hurt a little, but once it's in place you'll have no pain. It can stay in for a few days or be removed right after your treatment.

### *PICC line*

A PICC line is a long, thin silicone tube. It's put into a vein above where your elbow bends. A specialist nurse will insert it in an outpatient ward or a clinic. One end is fed up a vein in your arm into a large vein in your chest. The other end comes out around your elbow and can have one, two, or three tubes (*lumens*). Treatment is given through the lumens. The PICC line will be taped with a dressing so it doesn't move. PICC lines can stay in for up to two years. Sometimes PICCs are called *central venous access devices* (*CVADs*).

### *Port*

A port is a small medical device that is implanted under the skin in your chest, just above your heart. It's a thin, flexible silicone tube with a silicone disk on the end. The disk is the ‘port’. When it heals, you can see and feel the port under your skin, but there are no external tubes. Your nurse will access the port each time you need blood tests or treatment by inserting a short needle into the silicone disk. Ports can stay in for years and, once healed, require little care from you. Ports are also called *infusaports* or *portacaths*.

### *Central line*

A central line is a long, thin silicone tube. It’s also called a *Hickman® line*, a *central venous catheter (CVC)*, or *a central venous access device (CVAD)*. One end of the tube sits in a large vein above your heart. The other end, which is capped, comes out of your chest. It often has one, two, or three tubes (called *lumens*) coming off that line. 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:** there is no evidence of lymphoma and no sign of it reappearing even after many years.

**Complete response/remission (also called remission):** where the treatment has been successful and so much of the lymphoma has been destroyed that it can no longer be detected using all available tests. The length of time that a remission lasts varies from person to person and the lymphoma can come back, even after a long time.

**Partial response/remission:** where the lymphoma shrinks to less than half its original size following treatment, but some disease remains in the body.

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

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

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

**Disease progression**: 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 might 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:**

- the type of NHL you have
- the stage of your NHL
- which parts of your body are affected
- your age
- your general health
- blood test results, and
- your wishes.

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

1. Active observation ('watch and wait') involves regular check-ups but no treatment
2. Supportive care controls symptoms of NHL for some subtypes
3. Standard drug therapies, such as chemotherapy
4. Radiation therapy
5. Stem cell transplant replaces bone marrow cells with new, healthy cells
6. 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’ll just have regular check-ups to carefully 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 a few factors when deciding on treatment. These include where the lymphoma has spread to, how large the areas of lymphoma are, if you have any symptoms, and 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 when they are diagnosed. 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. These might involve using more chemotherapy and/or immunotherapy, using different chemotherapy and/or immunotherapy, or using 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 don't need to start any treatment as they don't have any symptoms. Your haematologist may recommend regular check-ups to keep an eye on your health. Your GP may monitor your NHL with blood tests as part of your active follow-up. How often, will depend on any changes in your blood counts, symptoms, and general health. This is called 'watch and wait'.

## Supportive care

Supportive care prevents and treats symptoms and side effects. It includes emotional and social support too. The goal is to improve symptoms of your NHL, but it doesn't treat the disease itself.

## Blood transfusions

If you notice symptoms of anaemia, talk with your treatment team. You may need a blood transfusion or an effective alternative to transfusion (for example, replacement therapy for iron deficiency). Transfusions are usually given by a nurse in a clinic or in an outpatient ward of a hospital. The nurse will use your CVAD or will insert a 'drip' (a *cannula*), into a vein in your arm. 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 of packed red blood cells.

## 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 lab. They are used to boost low blood counts.

In Australia, white blood cell growth factors are given. Neutrophils are white blood cells that help fight infections. A growth factor called *granulocyte colony stimulating factor* (also known as G-CSF) makes the bone marrow produce more neutrophils. This is predominantly used when people are being treated with chemotherapy.

Growth factors don't usually cause any major side effects, but some people may have chills, headaches, and bone pain after an injection.

## Antibiotics

When your white blood cell count is low you have a higher risk of getting infections. If you do, it's important to be treated as soon as possible. If you develop signs or symptoms of infection, your treatment team will probably prescribe antibiotics; either in tablet form or given via a 'drip' straight into your bloodstream (IV).

## Antimicrobial and antiviral medicines

When you start chemo or if you are preparing for a stem cell transplant, you may be given antimicrobial medicines.

These types of medicines will be taken to prevent infection. This is called *prophylaxis*, or you might hear the drugs referred to as *prophylactics*. These 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. Only some vaccines are safe and these are called *inactivated* vaccines. You will need to check with your treatment team when to have them. You should not have any *live* vaccines.

## Chemotherapy

Chemotherapy medications (also called *chemo*), sometimes also called cytotoxic (which means ‘cell killing’) medications, make cancer cells stop growing. They either kill the cells or stop them from dividing, replicating, and reproducing. They also damage normal cells, but these cells can repair and recover.

Unlike supportive care, which treats symptoms, chemo treats the actual disease. Because of this, it’s often called *disease modifying* treatment.

Chemo can be given as tablets, injections, or infusions via a drip (IV). The type of chemo given depends on the type of lymphoma. It’s common to be on more than one chemo drug 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 a clinic, outpatient ward, 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. Chemo cycle times depend on the drug. The number of treatment days and the number of cycles can be different due to the drug or the disease being treated.

You will usually have a blood test just before each chemo cycle starts, to check your blood cell levels are high enough. Your treatment team will give you the blood forms at each visit and will tell you which day is best to have the tests.

## Chemotherapy for NHL

To treat NHL, there are a few chemo drugs available. **Your haematologist will recommend chemo depending on:**

- your subtype of NHL and its stage
- your overall health
- your age
- whether it is your first treatment, or your NHL has come back after remission (relapsed), and
- whether you are preparing for a stem cell transplant. *You can read more about stem cell transplants later in this booklet.*

Chemo for NHL usually involves a combination of a few drugs.

Most of the chemo is given via a drip (IV). You will be given medicine to help with feeling sick (nausea).

### *Chemotherapy side effects*

Chemotherapy kills cells that multiply quickly, like lymphoma cells. It also damages fast-growing normal cells. These include hair cells and cells that make up the tissues in your mouth, gut and bone marrow. You may get chemo side effects because of the damage to the normal cells.

Everyone gets different side effects with chemo. Some patients feel a lot better when the chemo starts – for example as their ‘B-symptoms’ disappear. You may have no side effects, or one or more of them, and they may change over time.

Don’t be concerned if you don’t get side effects – it doesn’t mean that the chemotherapy isn’t working. Also, don’t be resigned to the expectation that you need to suffer them. It is likely that the side effects can be greatly improved by supportive medications (e.g. anti-nausea).

**Which side effects you have, and how severe they are, depends on:**

- your type of NHL
- your chemo
- 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 your bone marrow's ability 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 circulating red blood cells cause anaemia. You may feel tired, short of breath, and look pale. Take it easy and contact your treatment team. You might need a blood transfusion to help your levels recover.

When your platelets are low, you can bruise and bleed more easily. If you notice these signs, please let your treating team know.

When your white blood cell count (neutrophils) is too low, this puts you at a higher risk of developing an infection.

## 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.

## Feeling sick – nausea and vomiting

Nausea (feeling sick to your stomach) and vomiting are common side effects, but you will be given medicine to prevent or manage them. If you do feel nauseous, even with medicine to help, do not hesitate to contact your treating team to ensure it is managed and you can continue eating and drinking.

Keep an eye on your weight if you are eating less than usual. If you find it difficult to eat, 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 make you not enjoy 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

You might have cramping, wind, bloating, diarrhoea, or constipation. You will be given medication to help. Tell your treatment team if you are constipated or if it's painful or hard to pass faeces, and if you have haemorrhoids, don't strain. Sometimes making a few changes to what you eat can help too. 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 information 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. Set up some ways to remember things, like writing them down. Talk to your support network too, so they know what's going on.

## Hair loss (*alopecia*) and thinning

The thought of losing our hair is scary. Hair thinning or loss is a very common side effect of chemo, but not all chemo causes it. 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. There is no correlation between alopecia and the effectiveness of chemotherapy.

You might find your scalp is itchy as you lose your hair, but this will pass. There are some great wraps, turbans, and beanies available. Your nurse can give you information on where to find them, and about where to get wigs.

## 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 at any time during treatment. Tell your treatment team if you feel tingling, numbness, burning, or pins and needles in your fingers or toes. It might be hard to do up buttons or to grip things. If this happens, your treating specialist may reduce the dose or omit the offending chemo drug.

## Sun sensitivity

Some chemo drugs make you more prone to sunburn. You can go outside, but avoid direct sunlight.

## Managing chemo side effects

| Potential side effects | What might help |
|---|---|
| **Low red blood cells (anaemia)** | • you may be given a blood transfusion or recommended supplements |
| **Low platelets** | • avoid sharp objects in your mouth like chop bones or potato chips<br>• be careful not to cut or injure yourself<br>• use a soft toothbrush<br>• use an electric razor<br>• wear gloves and closed shoes in the garden |
| **Low white blood cells (neutrophils) – risk of infection** | • talk to your treatment team about vaccinations<br>• avoid crowds<br>• keep away from people who are sick and might be contagious (colds, flu, chicken pox)<br>• eat food that has been properly prepared and freshly cooked<br>• don’t clean up pet faeces<br>• wear gloves in the garden<br>• don’t swim in public pools, lakes or rivers |

| | |
|---|---|
| **Feeling sick – nausea and vomiting** | • eat smaller meals more often during the day<br>• try cool or cold food, like jelly<br>• let someone else cook for you<br>• drink ginger ale or soda water<br>• avoid strong smells<br>• you'll be given medicine to help |
| **Change to taste** | • add a little more sugar to sweet foods<br>• add a bit more salt to savoury foods<br>• if you have a metallic taste, try rinsing your mouth |
| **Mouth problems – mucositis** | • use a soft toothbrush and mild toothpaste<br>• brush every time after you eat<br>• use salty water, sodium bicarbonate in water, or alcohol-free mouthwash<br>• continue to floss but stop if your gums bleed |
| **Bowel changes** | • drink plenty of fluids<br>• get some dietary advice from your treatment team<br>• if you're constipated, don't strain<br>• if you have haemorrhoids, do not push on them<br>• tell your treatment team, you'll be given medicine to help |
| **Skin problems (rashes, sensitivity)** | • your treatment team will recommend body washes and creams that are safe to use<br>• avoid soaps and perfumes on the affected area<br>• take cooler showers or baths |
| **Fatigue** | • see later in this booklet for more info<br>• rest or nap when needed<br>• take regular gentle exercise |
| **Bone, joint, or muscle aches and pains** | • talk to your treatment team<br>• some gentle exercise, like walking, may help<br>• you may be given medicine to help |

| | |
|---|---|
| **Chemo brain** | • keep a notebook handy to write things down<br>• ask your pharmacist to Webster-pak your medications<br>• take regular gentle exercise<br>• socialise – tell your loved ones what's going on |
| **Hair loss and thinning** | • prepare your family and friends<br>• use a soft hairbrush and a mild baby shampoo<br>• pat your hair dry gently with a towel<br>• cut your hair shorter or have it shaved when you start chemo<br>• use an electric shaver<br>• avoid using heat or chemicals; don't dye or blow dry your hair<br>• use sunscreen on your scalp |
| **Sun sensitivity** | • cover up with long sleeves and long pants<br>• wear sunglasses and a hat or beanie to protect your scalp<br>• talk to your nurse about which sunscreens are best to use<br>• avoid sun exposure at high UV times of the day |

## Corticosteroids

During treatment you will likely be given drugs called *corticosteroids* or '*steroids*' for short. Common steroids are prednisolone and dexamethasone. They can be given in tablet form and/or via drip (intravenously). They help chemo drugs destroy lymphoma cells and reduce the risk of allergic reaction to some chemo drugs.

### Steroid side effects and how to deal with them:

- 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.

## Immunotherapies

Immunotherapy, sometimes called biological therapy, is a type of cancer treatment that works by boosting a person's own immune system to fight lymphoma by recognising and attacking lymphoma cells. Immunotherapy is currently approved in Australia for some types of blood cancers and is also being trialled for other cancers.

## Monoclonal antibodies

Monoclonal antibodies are a type of immunotherapy. The types of monoclonal antibodies used for NHL are specifically targeted to lymphocytes. They work by attaching to cancer cells and either killing them directly or assisting the immune system to destroy those cells. They also make cancer cells grow more slowly.

## Targeted therapies

Targeted therapies are specialised treatments that target the survival advantages that lymphoma develops. Some of these treatments may directly target the mutations on the cell surface or inside the lymphoma cells, whilst others may slow down their growth or speed up the rate at which the cancerous cells die. These treatments cause far less harm to normal cells than chemo.

Targeted therapies may be given by themselves or added on to standard therapies. Due to their nature and cost, targeted therapies are generally used in highly specific circumstances in routine practice or may be available on a clinical trial.

## Radiation therapy (radiotherapy)

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

Radiotherapy can be used in a few different ways to treat NHL. In some cases, single areas of lymphoma may be treated using only radiotherapy. Radiotherapy is also used to treat areas of bone that have become weak due to lymphoma. It helps reduce bone pain and the risk of bone fractures. Radiotherapy is also used to 'consolidate' chemo-immunotherapy, e.g. at a 'bulk' or extranodal site.

### *Before you start*

Before you start radiotherapy, you'll meet with the radiation oncologist (specialist in treating people with radiotherapy). You'll discuss treatment options and goals, and you may have a physical examination.

Next, you'll have a *simulation session*. You'll have scans and your radiation oncologist and radiation therapists will work out what position you will be in for all your radiotherapy treatments. They'll also work out your dose of radiation. You may end up with small tattooed dots on your skin, which help guide the treatment.

### During treatment

Treatment is usually short: allow 15-30 minutes per treatment. Most of this time the treatment team will be setting you up for your session. You'll be alone in the treatment room, but your treatment team will be able to hear and see you. If you're feeling nervous, you might like to bring along some music to help you relax.

If necessary, important structures like your heart and lungs will be shielded, so they're not affected by the treatment.

You'll be positioned the way you were in your simulation session. The radiation machine will move around you to deliver the treatment and it'll make a buzzing sound. The radiation beam is on for only a couple of minutes. It's important to stay still while the treatment is taking place.

You don't see or feel anything during the actual treatment and it's painless.

You may have short (one or two treatments) or longer courses of radiotherapy depending on your needs. Longer courses are usually given in small doses (called fractions) every weekday (Monday to Friday) over a few weeks.

### *Side effects*

Radiation therapy can cause side effects. The side effects vary from person to person. 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 later in this booklet*
- 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, loose stools, 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.

### *CAR T-cell therapy*

CAR T-cell therapy is an emerging treatment that is a type of immunotherapy and gene therapy. It involves changing the genetic make-up of some of your own normal T-cells, 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 isolate 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 multiply at sites of lymphoma.

## 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.

## Stem cell transplantation

Stem cell transplants (also called *bone marrow transplant*, or a *haemopoietic cell transplant* or *HCT*). As a stem cell transplant has its own particular risks and side effects, it is only used in certain situations where the benefits are judged to outweigh he risks. Usually stem cell transplantation is reserved for cases that have not responded well to chemo-immunotherapies.

### *Autologous* stem cell transplant

An autologous stem cell transplant starts with giving induction chemotherapy to kill the lymphoma. Once the chemotherapy has passed through your system and enough lymphoma cells as possible have died so your lymphoma is considered stable or in remission, your own bone marrow stem cells are collected. These stem cells are frozen and stored until after you've had a further big dose of chemotherapy which will wipe out your bone marrow, then the stem cells are thawed and returned to your bloodstream. They then home in on the empty bone marrow and regrow into normal blood cells. Autologous transplants are more common in people with lymphoma than allogeneic transplants.

### *Allogeneic* (donor) stem cell transplant

Unlike autologous stem cell transplantation, an allogeneic stem cell transplant is a form of immunotherapy. The healthy stem cells are donated. Usually, a brother or sister who has the same tissue type as yours is the donor. They just need a blood test to see if they are a match to you. If they are, they are called *HLA matched donors*. This procedure is called an allogeneic (donor) stem cell transplant. The stem cells can also come from someone who is not related but is a match.

The goal of a stem cell transplant is twofold. First, is to create an immune response called a *graft-versus-lymphoma* (*GVL*) effect. The donated stem cells make their own immune cells, and these create a new immune system. These immune cells kill any cancer cells that are left after you've had the high-dose chemotherapy.

Second, is to restore normal blood cell growth with healthy donated stem cells after 'conditioning' chemo destroys your abnormal cancerous stem cells.

**Stem cell transplant side effects include:**

- low blood counts
- all the same side effects as chemo, but more severe
- graft-versus-host disease for allogeneic transplants, where the new immune system attacks normal cells in the body instead of or as well as the lymphoma.

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

You can find out more about stem cell transplants in our booklet *Allogeneic Stem Cell Transplants* and on our website.

## Clinical trials

Clinical trials (also called *research studies*) test new treatments and often provide early access to promising therapies that aren't routinely available. Results from the new agent (or combination of agents) are compared against current (or standard) treatments to see if the new treatment works better. They also check for the new treatment's side effects. Many clinical trials are randomised, which means some patients receive the new treatment and others the current standard of care treatment.

Clinical trials provide important information about how treatments can be improved. Sometimes people on clinical trials (called 'participants') have access to expensive new treatments that aren't available on Australia's PBS.

Your haematologist may suggest you join a clinical trial. Before you can start, you will need to give informed consent. This shows that you understand the risks and benefits of the trial treatment.

Clinical trials are run through hospitals and clinics, just like other treatments. You will have a clinical trial nurse as part of your treatment team.

Clinical trial participation is purely voluntary. If you are offered a clinical trial, make sure you understand how your treatment will be different compared to what is generally given (standard of care treatments). Be sure to ask any questions you have before deciding whether to participate.

*You can search current clinical trials at:*

***Australian Cancer Trials:*** *australiancancertrials.gov.au*

***ANZ Clinical Trials Registry:*** *anzctr.org.au and*

***ClinTrial:*** *clintrial.org.au*

**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.

# Complementary therapies

Complementary and alternative medicines (CAM) also known as integrated therapies are not standard medical treatments. However, some people find that they help with side effects.

These therapies should ‘complement’ or be done alongside medical treatment after consultation with your treatment team.

No complementary or alternative treatment on its own can treat NHL. They may help with some symptoms or side effects.

# Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called *cancer-related fatigue*. It can be hard to describe to people who haven't felt it. It's more than being tired, its 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 also 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.

## Tips for managing fatigue

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

A positive sleep routine, pre-sleep relaxation techniques, napping if tired during the day for up to an hour, regular moderate exercise or movement, eating well, drinking plenty of water, and avoiding use of electronic equipment, such as computers late at night, can be very helpful in improving sleep and reducing fatigue.

While you're managing your fatigue, jot down what time of day you have the 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.

# 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
- success rates
- the risks
- side effects of fertility treatments, and
- any costs.

### *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. Tell your treatment team right away if you are pregnant or think you may be.

There are several mainstream 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.

**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 supports your understanding of how to manage your side effects with medication prescribed.

**Accredited practising dietitian** - A university-qualified professional with ongoing training and education programs, who helps to support your recovery and manage challenges in your diet.

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

**Physiotherapist/Exercise physiologist** - Health professionals who specialise 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 here:

| | Contact name | Phone | Comment |
|---|---|---|---|
| Emergency | | | |
| GP | | | |
| Haematologist | | | |
| CNC/CCC | | | |
| Chemo Day Unit | | | |
| Pharmacist | | | |
| Dietitian | | | |
| Social worker | | | |
| Psychologist | | | |

***Useful website:*** *https://patients.cancer.nsw.gov.au/diagnosis/navigating-the-health-system*

# The new normal – what is it?

For many people, the start of treatment signals changes to life that include the day-to-day managing of a multitude of new activities and changes around treating and monitoring of your blood cancer. Frequent appointments with your health care team and regular follow up can be tiring and stressful for all.

Life is not exactly the same as it was before the blood cancer diagnosis. Everyday life changes for you and the people around you. Things that were once important may no longer be so, or 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 your new normal to live as good a life as possible while facing changes such as and not limited to:**

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

Seeking information, tools, and support, and accepting help to manage challenges that arise throughout a person's cancer experience is very important. Having this support can enable individuals to have a high quality of life throughout their blood cancer journey. 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 and is affected differently.

# Diet and nutrition

During treatment nutritional goals are designed to prevent or reverse malnutrition, avoiding weight loss (preserving lean body mass/ muscle) and to minimise side effects, such as decreased appetite, nausea, diarrhoea, dry mouth, and taste changes.

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

It is likely you will be encouraged to eat a high-energy diet to meet the changing metabolic demands of your body during this time. During chemo treatment you may experience complications that negatively affect your nutrition and hence your overall wellbeing, such as mucositis (ulcers in the mouth/throat and/or stomach).

You may be given drugs called corticosteroids, as part of your treatment. Steroids can cause weight gain through increased appetite stimulation and fluid retention (oedema) in your limbs, abdomen, and face.

**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. It's important to get advice from your health care team before you try to lose weight during treatment.
- **Get essential nutrients.** These include protein, carbohydrates, fats, 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 treating team may refer you to a dietitian. Community dietitians are also available, and your GP can arrange this through a care plan if your private health insurance doesn’t cover it.

# Exercise

With any blood cancer treatment, it is common to experience deconditioning; a physical and/or psychological drop in function. Having cancer doesn't mean you can't be physically active.

People with blood cancer should attempt to avoid inactivity and sedentary behaviour as much as possible and return to normal daily activities as soon as possible following diagnosis.

### What are the benefits of exercise/physical activity?

Strong evidence is available to show that exercise and physical activity improves outcomes for people with cancer across a range of dimensions including:

- cancer-related fatigue, pain, psychological distress, anxiety, depression
- in-bone health, cognitive, and cardiovascular function
- Health-related quality of life.

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

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

# Mental health and emotions

Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings and 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, and feeling isolated or lonely. Worrying about treatment, its success and side effects, or changes in your physical, lifestyle, and family dynamics can also impact your mental health.

Seeking help from your healthcare 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.

## Relationships/carers/family and friends

Undergoing treatment for a blood cancer can affect your role as a parent, partner, friend, and workmate, to name a few. You and all the people in your life will cope differently. Be open with your communication and encourage family and friends to be open with you.

Communicating effectively with family, children, friends, and a carer 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 many allied healthcare staff and not-for-profit organisations that can assist with support and information. The Leukaemia Foundation is one of them and can assist you, your carer or family in identifying who can help with different issues and how to contact them.

***Carers Australia:*** *carersaustralia.com.au*

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

***Canteen:*** *canteen.org.au*

***Redkite:*** *redkite.org.au*

# Work/finances/legal matters

## Finances

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

## A financial stocktake

When you become aware that you may lose your income or suffer a reduced income as a result of the ill health of you or an immediate family member, the first step should be 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 policy?
- Do you have money in the bank or a line of credit against your mortgage which can be drawn against?

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

# Seeking help

Financial advice around budgeting and what financial assistance is available to you can be discussed with a number of sources. Your local Leukaemia Foundation Blood Cancer Support Coordinator can help point you in the right direction.

**A few key other options to consider are:**

## Centrelink

If you expect to lose all or most of your income or your partner's income, the first organisation to contact is Centrelink. The earlier you make an application, the sooner you may receive some 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

If you are unable to make your regular payments on your mortgage as a result of serious ill health, it is important that you let the relevant organisations know as soon as possible. Most banks and other financial organisations have special arrangements for customers in financial hardship as a result of ill health.

## Other sources of help

Do not hesitate to discuss your financial circumstances with your treatment centre social worker or your private insurer. They may be able to assist with advice on deferring payments. Some of your household accounts may also have hardship support programs (like energy providers). 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 as one of its features. If you are not sure, give their helpline a call.

***Moneysmart:*** *moneysmart.gov.au*

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

# Legal matters

This information applies equally 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 we consider 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 for themself. 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, make personal, administrative and, if you choose, financial decisions.

An *Enduring Guardian (EG)* is another document where your trusted person can make decisions on your behalf regarding your health matters such as medical treatment, care, and protection, even if this decision overrides your wishes.

***Australian Guardianship and Administration council:*** *agac.org.au*

## Wills

It is very important to have specialist legal advice when preparing your Will. There are many questions and options your legal adviser will discuss with you which may not be immediately apparent. This is particularly important when you have dependent family members and you need to determine who will be responsible for them in the event of your death.

If you die without leaving a valid Will, you leave what is known as ‘intestacy’. Although you may feel your affairs are very simple and your immediate family will receive your assets, this is not necessarily true. Should you die intestate, distribution of your estate will be determined by a formula set down in legislation. If you already have a Will, you need to consider if it is still current.

## Advance Health Directive

This is a document you may complete to clearly indicate your wishes as to medical treatments you may or may not wish to receive in the event of a serious illness or accident. Although this is a lengthy document, it is simple to complete as it mainly 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, and you are also required to have a doctor 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
- Australian Guardianship and Administration Council

# More information & 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. |
| **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. |
| **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, bone marrow 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. |
| **bone marrow aspirate** | 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. |

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| **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. |
| **hypogammaglobulinaemia** | A problem with the immune system in which not enough gamma globulins are produced in the blood. This results in a lower antibody count, which impairs the immune system, increasing risk of infection. |
| **immune system** | The body's defence system against infection and disease. |

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| **immunotherapy** | 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. Immunotherapy is currently approved in Australia for some types of cancers and is also being trialled for other cancers. |
| **leukaemia** | Cancer that begins in blood-forming tissue, such as the **bone marrow**. It causes large numbers of abnormal blood cells to be made and to enter the bloodstream. |
| **leukocytes** | Also called white blood cells. These blood cells 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. |
| **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. |

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|---|---|
| **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:** | leukaemia.org.au |
| **Australian Cancer Trials:** | australiancancertrials.gov.au |
| **Australian New Zealand Clinical Trials Registry:** | anzctr.org.au |
| **eviQ Cancer Treatments Online:** | eviq.org.au |
| **Australian Red Cross Blood Service:** | mytransfusion.com.au |
| **Pharmaceutical Benefits Scheme:** | pbs.gov.au |
| **Lymphoma Australia:** | lymphoma.org.au |
| **ClinTrial Refer:** | clintrial.org.au |

## Question builder

☐ Who will be my main contacts? How do I best contact you/ them?
☐ What can I do to avoid infections?
☐ Can I have the flu shot and other vaccinations?
☐ Is it safe to take my supplements 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 via email: **info@leukaemia.org.au** or phone us on **1800 620 420**.

Leukaemia Foundation®

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**leukaemia.org.au**

♲ The Leukaemia Foundation cares about our environment. Please recycle or dispose of thoughtfully.