

Hodgkin lymphoma (HL)

A guide for people with HL and their support people

This booklet has been written to help you and your support people understand more about Hodgkin lymphoma.

We know you may be feeling anxious or overwhelmed if you or someone you care for has recently been diagnosed with Hodgkin lymphoma. 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 list of contents and choose which parts to read now. You can come back to read other parts later on. You may need more information, 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'll most often see will be haematologists and haematology nurses, and you'll need a regular GP, but you'll also meet pathology providers 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. They 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.

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Hodgkin lymphoma in brief

About Hodgkin lymphoma

Hodgkin lymphoma is cancer that develops in the lymphatic system and affects white blood cells called lymphocytes.

People with Hodgkin lymphoma have cells called Reed-Sternberg cells and Hodgkin cells. Hodgkin lymphoma 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.

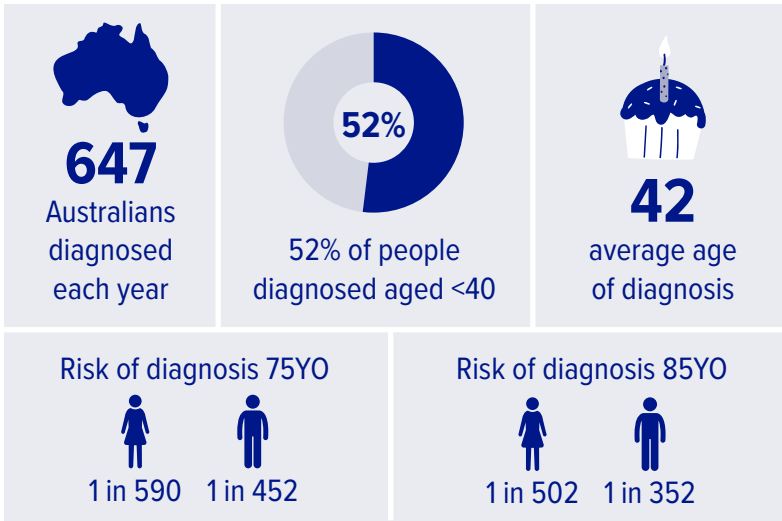
Symptoms of Hodgkin lymphoma include tiredness, weight loss, drenching night sweats, itching all over, swollen lymph nodes and enlarged organs, like the spleen.

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

Most people (80%) diagnosed with Hodgkin lymphoma are cured after initial treatment. Treatment is usually chemotherapy with or without radiotherapy. Some people have stem cell transplants.

In most cases we don't know what causes Hodgkin lymphoma. There is usually an acquired mutation in (change to) the genetic material of white blood cells called lymphocytes. While HL can be more common in some families it is not passed down like other genetic disorders. There is no way to prevent Hodgkin lymphoma and you can't catch it or pass it on.

Who gets Hodgkin lymphoma



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 will consider many factors when considering your prognosis. Some of these are the subtype of Hodgkin lymphoma you have, its stage, the number and location of lymph nodes affected, your age and your overall health.



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

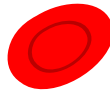
All about blood

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.

Platelets
Support blood clotting
to stop bleeding



Red Blood Cells

Carry oxygen for the body to produce energy



White Blood Cells

Form part of the immune system

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?

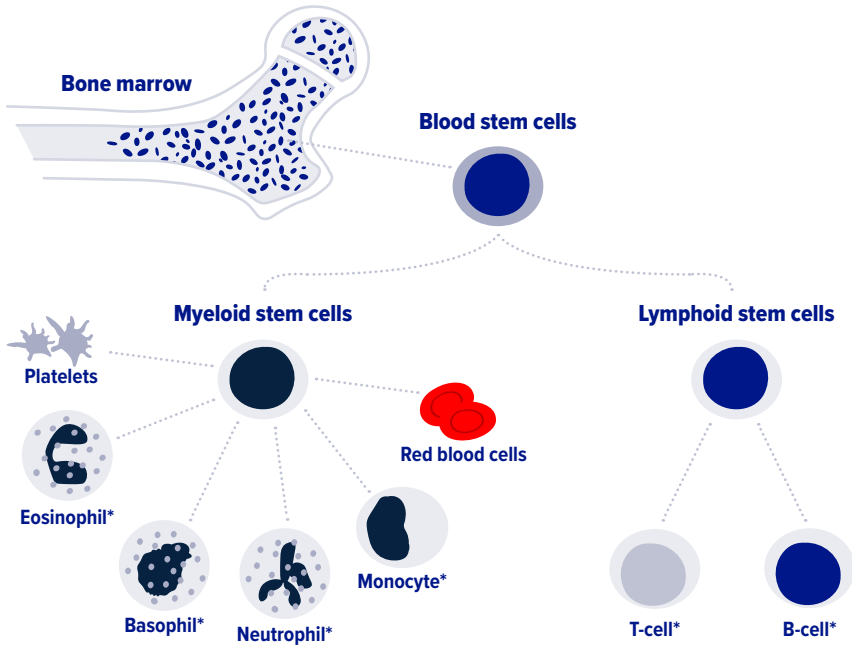
Bone marrow

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

In children, haematopoiesis 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.



Lymphoid stem cells develop into two types of white cells. These are the cells affected in Hodgkin lymphoma.

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.

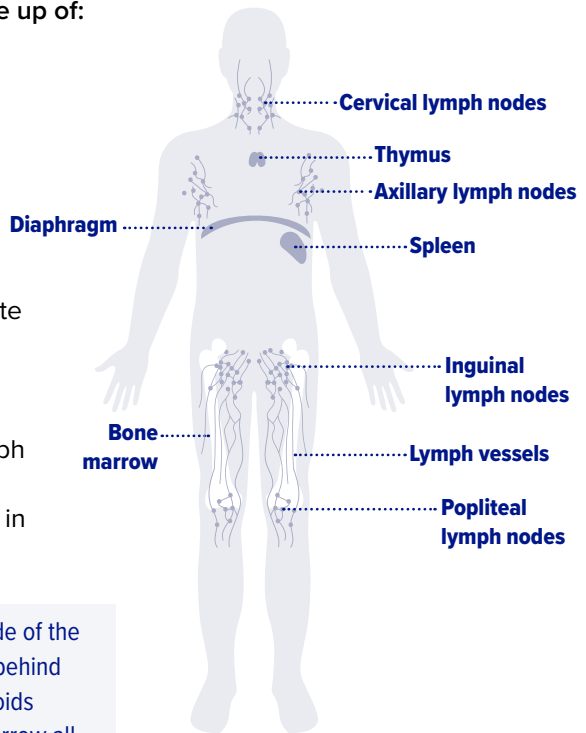
All about the lymphatic system

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: Hodgkin lymphoma and non-Hodgkin lymphoma.

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

All about Hodgkin lymphoma

What is Hodgkin lymphoma?

Hodgkin lymphoma is a type of cancer where people have cells called Reed-Sternberg cells. They are abnormal B-cells (lymphocytes), which are big and 'owl-like' under a microscope. There are also Hodgkin cells, which are smaller than Reed-Sternberg cells but larger than normal lymphocytes.

Hodgkin lymphoma can affect a single lymph node or a group of lymph nodes. 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, Hodgkin lymphoma can spread via the lymphatic system and the blood to almost any part of the body.

Subtypes of Hodgkin lymphoma

Hodgkin lymphoma is broken down into five subtypes. The WHO has a system that defines the subtypes. Your haematologist will use the WHO system to work out which subtype you have, and the right treatment for you.

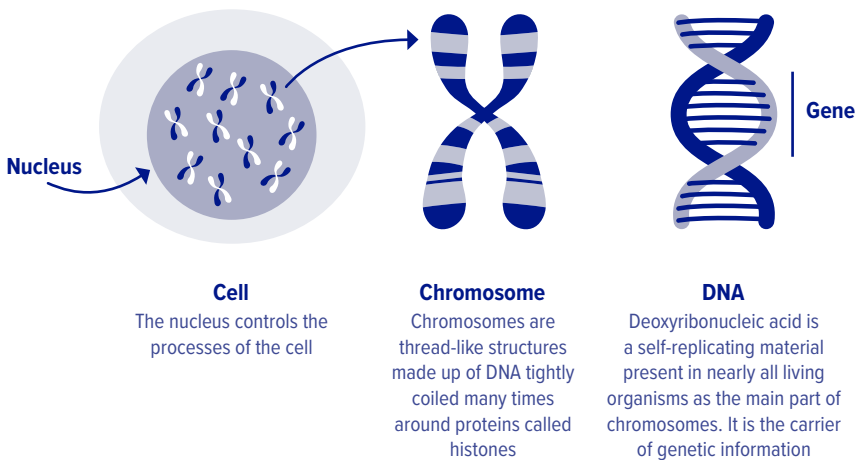
Subtype	Features
Nodular sclerosing	Most common sub-group. Common in adolescents and adults under 50. Usually involves the lymph glands of the neck and chest.
Mixed cellularity	More commonly seen in older people (over 50 years).
Lymphocyte-rich	Diagnosed at an early stage in adults and has a low relapse (disease returns after treatment) rate.
Lymphocyte depleted	Disease tends to be more widespread at diagnosis.
Nodular lymphocyte predominant	Usually slow growing, diagnosed earlier, and treatment differs to other subtypes. Has lymphocyte-predominant cells, which have a popcorn shape.

How does Hodgkin lymphoma 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 had a malignant

(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 about 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 (cancer cells) due to genetic changes (mutations) within the cells.



Causes of Hodgkin lymphoma

In most cases, there is no specific cause of Hodgkin lymphoma. Gene mutations in cells happen all the time. Healthy cells have clever ways of stopping them from causing problems in the body. There are gene changes linked to Hodgkin lymphoma.

Why a particular person at a particular time gets Hodgkin lymphoma is not really known. But some things (*risk factors*) give some people a higher risk of developing it.

Known risk factors

- **Age** – it's more common in people aged 20 to 34 or over 70.
- If you have a **close family member (parent or sibling) with Hodgkin lymphoma**, you have a slightly higher risk, due to genetic factors. It's a very small risk and most people with close relatives with lymphoma will not develop the disease themselves.
- Sometimes a virus called **Epstein-Barr virus**, which causes glandular fever, has been linked to lymphoma.
- A **weak immune system** may increase risk. Conditions like HIV or drugs used to suppress immunity after organ transplant may weaken immunity.
- People who have had a type of **non-Hodgkin lymphoma** have an increased risk of developing Hodgkin lymphoma.

Symptoms of Hodgkin lymphoma

Most people with Hodgkin lymphoma notice enlarged lymph nodes.

You may have general symptoms, such as:

- fevers
- heavy (drenching) night sweats
- fatigue (extreme tiredness not relieved by rest)
- dizziness
- weight loss for no reason
- itching all over.

Swollen lymph nodes

You may feel small, rubbery lumps in your armpits, on either side of your neck, near your collarbone and/or in your groin. They usually won't be painful, although they can cause other symptoms as they grow. For example, if you have an enlarged lymph node in your neck, you may have a cough. There are internal lymph nodes too, in your chest and belly. They might swell but can only be seen with scans.

Low blood counts

Less than 10% of presenting symptoms due to Hodgkin Lymphoma are because of low normal blood cell counts because the 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.

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

Anaemia is caused by low red blood cells. Red blood cells carry 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 support your immunity.

You may have symptoms from each of these groups because all your blood cell types can be low due to Hodgkin lymphoma (which 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.
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

Enlarged spleen and liver

Your spleen is an organ located in the top left of your abdomen, near your rib cage. It acts like a sponge for blood cells. It stores blood cells but can also make them. If your spleen starts making blood cells it may swell up. 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 in the top right of your abdomen.

How is Hodgkin lymphoma diagnosed?

The diagnosis of Hodgkin lymphoma requires a lymph node biopsy and, for some people, a bone marrow biopsy. Sometimes more than one biopsy is required to get the diagnosis. Some symptoms of Hodgkin lymphoma, like weight loss, are part of many conditions. Over recent years, the diagnosis and stage of Hodgkin lymphoma has become increasingly important to provide clinicians with all of the information they need to make the best treatment decisions for each patient. It is important for the clinician to understand the exact subtype classification (if applicable) and stage for treatment and prognostic decisions. You may need a few types of tests before the Hodgkin 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 Hodgkin lymphoma, like swollen lymph nodes or swollen organs (like your spleen).

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. It's sent to the lab, where a haematopathologist (a blood specialist) will look at the blood cells under a microscope.

ESR (erythrocyte sedimentation rate): Used as a "marker" of prognosis in Hodgekin Lymphoma, this blood test shows how long it takes for red cells to fall to the bottom of a tube in the lab.

Blood chemistry tests

Blood chemistry tests measure the levels of different chemicals in your body. These blood tests will often be taken at the same time as your FBC. Some substances that may be tested for will be:

Substance tested	What it indicates
Creatinine	Kidney function
Electrolytes	Kidney function
Blood urea nitrogen (BUN)	Kidney function
Uric acid	Cell breakdown
Lactate dehydrogenase (LDH)	Blood cell damage

Lymph node biopsy

When you have a lymph node biopsy, your treatment team removes all or part of a lymph node. 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.

There are two main ways a lymph node biopsy is done. A **core biopsy** involves a CT scan or an ultrasound to help the doctor find the right place to take the biopsy.

The core biopsy will take around 30 minutes. You'll be able to go home the same day but shouldn't drive, so arrange for transport home.

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 a general anaesthetic. You'll 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 results of the test. In some cases the initial biopsy may not provide enough information to accurately diagnose lymphoma or the particular subtype. Your treatment team will organise a repeat biopsy if needed – either from a different site or taking a larger amount of tissue. It is very important that the biopsy is accurate in order to determine the best course of treatment.

Staging tests

Imaging tests

CT scans

CT scans show three-dimensional (3D) images of parts of your body. They can find tiny changes in tissue density (thickness). 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 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-CT scans

For a PET scan radioactive glucose (sugar) is injected into a vein in your hand or arm. Special cameras trace the glucose as it moves through your body. They can see areas affected by lymphoma. PET-CT helps to stage your lymphoma. You will have them before, during and after treatment to check how it is going.

Bone marrow biopsy is generally no longer required for staging in Hodgkin lymphoma, and has largely been replaced by PET-CT scans.

Heart and other tests

Before you start treatment, you might have an echocardiogram or a MUGA. Both tests take pictures of your heart to check how well it pumps blood. You may also have an electrocardiogram (ECG) to check the electrical activity (rate and rhythm) of your heart.

Some people may also have a lung function test, or a 24-hour urine collection for testing.

What happens next?

After diagnosis

When all your test results have been reviewed, you'll meet with your haematologist to discuss your Hodgkin lymphoma and treatment goals and options. Your haematologist will work out the stage of your lymphoma too. It's natural to feel scared, confused or sad. You'll hear a lot of information and it can be overwhelming.

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

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.

There are four stages of Hodgkin lymphoma. Your haematologist will work out which stage you are at.

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 is only in one area. This can be one group of lymph nodes or one organ/area outside the lymph nodes
Stage 2	Lymphoma affects two or more groups of lymph nodes or an organ/area outside the lymph nodes on the same side of (above or below) the diaphragm*

Stage 3	Lymphoma is in groups of lymph nodes and/or an organ or other area both above and below the diaphragm*
Stage 4	Lymphoma has spread outside the lymphatic system, for example to the bone marrow, lungs, liver and/or skin

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

A, B, E or S?

Once you have your stage, it will have a letter after it that refers to your symptoms when you were first diagnosed. If you have no symptoms, the letter 'A' will appear after the stage of lymphoma, for example stage 2A. If you have symptoms like 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' is used when lymphoma has spread to an area or organ outside the lymph nodes, for example 4E. The letter 'S' stands for spleen.

Venous access for treatments

Many Hodgkin lymphoma treatments are given directly into a vein (*intravenously*, or *via IV*). There are two broad ways to provide access to your bloodstream- 1) through the peripheral veins in your arms or 2) through a central vein in your chest. Your treatment team will discuss them with you before you start treatment so you can decide which is best for you.

Peripheral intravenous cannula

This is the most common way to access a peripheral vein. 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. 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 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. It will be taped with a dressing so it doesn't move. PICC lines can stay in for weeks to months. Sometimes PICCs are called *central venous access device (CVADs)*. PICC lines require regular dressing changes and you should discuss their care with your treatment team.

Port

A port is a small device that is planted under your skin in your chest, just above your heart. It's a thin, soft silicone tube with a silicone disk on the end. The disk is the 'port'. It's inserted in day surgery and will take about a week for your skin to heal over it. 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 with a short needle into the silicone disk. The needle (sometimes called a gripper) has a line that's connected to your treatment. The needle is removed right after you have treatment. Ports can stay in for years. 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. There are a few types of treatment responses defined by the International Lymphoma Working Group. In most cases of Hodgkin lymphoma the goal of treatment is cure.

- **Cure:** there is no evidence of lymphoma and no sign of it reappearing even after many years (usually five years). With treatment, most people with Hodgkin lymphoma can be cured.
- **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 there is still some remaining in the body.
- **Stable disease:** where the lymphoma is stable and is not getting any better 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.

Treatments and side effects

Your haematologist will recommend treatment based on:

- the stage of your Hodgkin lymphoma
- 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 Hodgkin lymphoma. **Your treatment plan may include one or more of these:**

1. Supportive care
2. Standard chemotherapy drugs
3. Radiation therapy
4. Stem cell transplant replaces bone marrow cells with new, healthy cells.
5. Immunotherapy – which uses the body’s immune system to help fight the disease
6. Clinical trials

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

Treatment by stages

Early-stage disease

Most people with early-stage Hodgkin lymphoma (stages 1 and 2) who have treatment are cured. Early-stage disease is usually treated with or a combination of chemo and radiotherapy or chemotherapy alone for 2-4 months.

Advanced-stage disease

Advanced-stage Hodgkin lymphoma (stages 3 and 4) is usually treated with more intensive chemotherapy. For some people, the chemotherapy will go on for six months or longer. Radiotherapy is usually not required.

Relapsed disease

If the lymphoma comes back (relapses) you may have more treatment. The choice of chemotherapy will generally be different, and you may have high-dose chemo followed by a stem cell transplant. The treatment options will depend on your age and overall health, and on how long the lymphoma was in remission.

Hard-to-treat (resistant or refractory) disease

Lymphoma cells can be resistant to treatment. This means you don't see the changes you would expect after treatment. Different therapies may be tried. 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.

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 Hodgkin lymphoma, but it doesn't treat the disease itself.

Blood transfusions

If you notice symptoms of anaemia, tell your treatment team. You may need a blood transfusion. Blood transfusions are slow injections of blood into a vein (intravenously, or IV). Transfusions are usually given by a nurse in a clinic or in an outpatient ward of a hospital. The nurse will use your CVAD (a device that gives access through a central vein in your chest) or will insert a 'drip'

(a cannula), a plastic tube, into a vein in your arm. The cannula connects to a bag of blood (called packed red blood cells). 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. Your treatment team will probably prescribe antibiotics, either in tablet form or given via 'drip' straight into your bloodstream (IV).

Antifungal and antiviral medicines

When you start chemo or if you are preparing for a stem cell transplant, you may be given antifungal and/or antiviral 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*. They will usually be in tablet form and your treatment team will tell you how often and for how long you need to take them.

Vaccines

Vaccines 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.

All about 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 cancer. It’s common to be on more than one chemo drug at a time. Some people have chemo alongside other therapies like targeted therapy, immunotherapy, surgery or radiation therapy. You can take some tablet chemo at home and may have injections or IV chemo in a clinic, outpatient ward or as an inpatient in hospital.

Intravenous 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.

Chemotherapy for Hodgkin lymphoma

There are a few chemo drugs for Hodgkin lymphoma. **Your haematologist will recommend chemo depending on:**

- your stage of Hodgkin lymphoma
- your overall health
- your age
- whether it is your first treatment or your Hodgkin lymphoma 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 Hodgkin lymphoma usually involves a combination of a few drugs. There are combinations for people with early-stage and advanced-stage lymphoma, for relapsed or refractory lymphoma, and for people in certain age categories who may not handle some side effects. Your haematologist will also consider if you are suited to or you have already had a stem cell transplant.

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 get chemo side effects because of the damage to the normal cells.

Everyone gets different side effects with chemo. You may have no side effects, or one or more of them, and they may change over time.

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

- your type of Hodgkin lymphoma
- your chemo
- your overall health and wellbeing.



You can find more information on chemo side effects and how to manage them on our website.

Immunotherapies

Immunotherapies are sometimes called *biologic therapies*. They use a part of your immune system to fight cancer. In this case, antibodies are created in a lab. In your body, antibodies fight infection by targeting parts of cancer cells to change how they grow.

Monoclonal antibodies

Monoclonal antibodies are a type of immunotherapy. They work by attaching to cancer cells to tell the immune system to destroy those cells. They also make cancer cells grow more slowly.

Monoclonal antibodies for Hodgkin lymphoma may be used when standard treatments have not worked.

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 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 to help your levels recover.

If your platelets are low you can bruise and bleed more easily. If you notice these signs please let your treating team know. 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 damage the heart and nervous system, and puts stress on the kidneys, which try to rid the body of all the substances. Tumour lysis syndrome is a medical emergency. 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. Recovery will be different for everyone. There are no medicines to help with chemo brain but adaptive strategies can assist managing everyday life. 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. You might lose your head hair, your eyebrows and your eyelashes, but it's only temporary. Hair starts to fall out a few weeks after you start treatment and tends to grow back three to six months after it finishes.

You might find your scalp is itchy 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 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.

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 platelets	<ul style="list-style-type: none">• avoid sharp objects in your mouth like chop bones or potato chips• be careful not to cut or injure yourself• use a soft toothbrush• use an electric razor• wear gloves and closed shoes in the garden
Low white blood cells (neutrophils) – risk of infection	<ul style="list-style-type: none">• talk to your treatment team about vaccinations• avoid crowds• keep away from people who are sick and might be contagious (colds, flu, chicken pox)• eat food that has been properly prepared and freshly cooked• don't clean up pet faeces• wear gloves in the garden• don't swim in public pools, lakes or rivers
Feeling sick – nausea and vomiting	<ul style="list-style-type: none">• eat smaller meals more often during the day• try cool or cold food, like jelly• let someone else cook for you• drink ginger ale or soda water• avoid strong smells• you'll be given medicine to help
Change to taste	<ul style="list-style-type: none">• add a little more sugar to sweet foods• add a bit more salt to savoury foods• if you have a metallic taste, try rinsing your mouth

Mouth problems – mucositis	<ul style="list-style-type: none"> • use a soft toothbrush and mild toothpaste • brush every time after you eat • use salty water, sodium bicarbonate in water, or alcohol-free mouthwash • continue to floss but stop if your gums bleed
Bowel changes	<ul style="list-style-type: none"> • drink plenty of fluids • get some dietary advice from your treatment team • if you're constipated, don't strain • if you have haemorrhoids, do not push on them • tell your treatment team, you'll be given medicine to help
Fatigue	<ul style="list-style-type: none"> • see later in this booklet for more info • rest or nap when needed • take regular gentle exercise
Chemo brain	<ul style="list-style-type: none"> • keep a notebook handy to write things down • ask your pharmacist to Webster-pak your medications • take regular gentle exercise • use memory aids (lists, diaries, visual aids, phone reminders) • socialise – tell your loved ones what's going on
Hair loss and thinning	<ul style="list-style-type: none"> • prepare your family and friends • use a soft hairbrush and a mild baby shampoo • pat your hair dry gently with a towel • cut your hair shorter or have it shaved when you start chemo • use an electric shaver • avoid using heat or chemicals; don't dye or blow dry your hair • use sunscreen on your scalp
Sun sensitivity	<ul style="list-style-type: none"> • cover up with long sleeves and long pants • wear sunglasses and a hat or beanie to protect your scalp • talk to your nurse about which sunscreens are best to use • 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. Steroids are drugs that act like your body's own hormones. They can help treat many types of cancer, and they can keep you from having nausea and vomiting after a round of chemo. They can also prevent allergic reactions to other drugs and blood products.

Common steroids are prednisolone and dexamethasone. They can be given in tablet form and/or via drip (intravenously).

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.

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.

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 radiotherapy treatment: what to expect

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 of radiotherapy

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'll usually start to heal **4-6 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.

Follow up

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

Surgery

You will have day surgery if you have a central line or a port inserted for access. You can read more about access earlier in this booklet. You may also need day surgery for a lymph node biopsy.

Stem cell transplantation

Stem cell transplants are also called *bone marrow transplant*, or a *hemopoietic cell transplant* or *HCT*. This treatment is risky because it has very serious side effects. Your haematologist will work out if you need and can have a stem cell transplant.

Stem cell transplant involves having very high doses of chemotherapy before the transplant. The aim is to destroy the cancer cells in your bone marrow. These cells are then replaced with healthy stem cells.

Autologous stem cell transplant

Your own stem cells are collected when your lymphoma is stable or you are in remission. They're stored until after you've had chemo

when they're returned to your bloodstream. Autologous transplants are more common in people with lymphoma than allogeneic transplants.

Allogeneic (donor) stem cell transplant

The healthy stem cells have to be donated. Usually your 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*. The stem cells can also come from someone who is not related but are a match. *This type of transplant is rarely used for Hodgkin lymphoma.*

The goal of stem cell transplant is twofold. First is to create an immune response called a *graft-versus-leukaemia (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 (allogeneic/ donor transplant only)

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.

Donor lymphocyte infusions

Lymphocytes are white blood cells that help the body fight infection.

In donor lymphocyte infusion (DLI), the same person who donates blood stem cells for the allogeneic stem cell transplant donates lymphocytes. The goal is the same as a stem cell transplant, to create the graft-versus-lymphoma effect.

Donor lymphocyte infusions are sometimes used if Hodgkin lymphoma comes back (relapses) or gets worse after a stem cell transplant. The side effects are the same as for an allogeneic stem cell transplant.

Treatment follow-up

After you've finished treatment, you'll need ongoing follow-up tests. These will include a physical check-up and blood tests. Your haematologist will advise how often you'll have them depending on your stage, age and what treatment you've had. You might have them with your GP or in your hospital clinic.

Most people have follow-up appointments and blood tests:

- every three months for two to three years after treatment, then
- every four to six months until five years after treatment, then
- once every year.

You may have scans too, but not necessarily as often.

Some treatments have potential long-term or late side effects, so you may have tests for these. They include heart disease, hypothyroidism (low levels of thyroid hormones), other cancers, and fertility issues. *You can read more about fertility later in this booklet.*

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.

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

No complementary or alternative or alternative treatment on its own can treat Hodgkin Lymphoma. 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: fertileysociety.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 themselves. 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.

active disease	Where the disease is still present during treatment, or where it has relapsed.
allogeneic	Blood, stem cells, bone marrow, or other tissue transferred from one person to another. For example, an allogeneic stem cell transplant involves transplanting stem cells harvested from another person.
anaemia	A lower-than-normal number of red blood cells in the blood. It causes tiredness, paleness, and sometimes shortness of breath.
antibodies	Also called immunoglobulins. Proteins in the blood that recognise and bind to other substances called targets. Antibodies destroy their target (such as a virus) and prevent infection. Auto-antibodies or self-antibodies target your own cells and can destroy them.
autologous	Blood or other tissue derived from your own body. For example, an autologous stem cell transplant involves reinfusing stem cells that have been harvested from your own body.
baseline	A first measurement of a condition taken early on, used to compare over time to look for changes.
basophils	A type of white blood cell. They help fight infection
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.
chemotherapy	The use of drugs to treat cancer.
chromosome	Part of a cell that contains genetic information.
chronic phase	
coagulation	Process of changing from a liquid blood to a solid. Also called <i>clotting</i> . 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.
eosinophils	A type of white blood cell. They help fight infection.

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.
granulocytes	A kind of white blood cell. There are three types: eosinophils, basophils and neutrophils. They help fight infection.
growth factors	Proteins that control cell division and cell survival. Some are made in the lab and used as treatments, such as G-CSF.
haematocrit	The amount of blood that is made up of red blood cells .
haematologist	A doctor who specialises in diagnosing and treating blood disorders.
haemoglobin	A protein inside red blood cells that carries oxygen around the body.
haemopoiesis	The formation of new blood cells.
immune system	The body's defence system against infection and disease.
immunotherapy	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.
immunoglobulins	Also called antibodies . Proteins in the blood that recognise and bind to other substances called targets. Antibodies destroy their target (such as a virus) and prevent infection. Auto-antibodies or self-antibodies target your own cells and can destroy them.
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).

lymphocytes	A type of white blood cell that plays a role in the immune system
megakaryocytes	Very large bone marrow cells that break apart to form platelets .
molecular response	An improvement related to treatment where tests show fewer cells with the <i>BCR-ABL</i> gene.
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.
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.

resistant or refractory disease	Where the disease is not responding to treatment.
relapse	Return of the original disease after it has improved for a time.
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
ClinTrial Refer:	clintrial.org.au
Lymphoma Australia:	lymphoma.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 NL 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?

How you can help

The Leukaemia Foundation ensures every Australian with blood cancer gets access to the trusted information, best-practice treatment, and essential care they need. With no ongoing government funding, we rely on the generosity of the community to help support all Australians living with blood cancer.

We understand that everyone's personal situation is different, so below are some of the ways you and your family may like to get involved.

Give

Your donations help provide free support services to Australians affected by blood cancer, (like financial and practical assistance, education, counselling and accommodation), and drive some of Australia's most important—and life-saving—cancer research.

Become a Lifeblood Hero

With your regular monthly gift, you can be there every step of every day in every way, for people living with blood cancer. Your ongoing support helps ensure everyone everywhere has access to the life-saving treatment and support they need.

Leave a gift in your Will

After taking care of your loved ones, a gift in your Will is a direct and valuable way of helping transform the future for Australians with blood cancer allowing your support to live on as a lasting legacy.

Fundraise

Get involved in World's Greatest Shave, plan a special Light the Night or celebrate your Best-Birthday-Ever! You can even create your own personal fundraising initiative that is completely unique.

Volunteer

Our wonderful volunteers are a crucial part of our success—helping at our signature fundraising events, maintaining our accommodation centres or providing support with specialised skills.

Become a Leukaemia Foundation Member

You can make a difference to the future of blood cancer by joining a networked community who care about people living with blood cancer. Members are the lifeblood of the Leukaemia Foundation and play an important role in shaping the future of the organisation.

Partner with us

There are many ways your business can help people with blood cancer. Together, we can create a bespoke partnership that aligns with your organisation's objectives and corporate social responsibility.

Give blood, marrow and tissue

Stem cell transplants and blood donations save the lives of many people facing many blood cancer. Visit donateblood.com.au to register today.

**To find out more contact us today supporters@leukaemia.org.au
1800 620 420**

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.