

# Understanding Hodgkin Lymphoma

*(also known as Hodgkin's Disease)*

A guide for patients and families



Leukaemia  
Foundation

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## ACKNOWLEDGEMENTS

The Leukaemia Foundation gratefully acknowledges Lilian Daly for research and authorship of this booklet and the following groups who have assisted in the development and revision of the information: people who have experienced Hodgkin Lymphoma as a patient or carer, Leukaemia Foundation support services staff, nursing staff and clinical haematologists representing the various states and territories of Australia. The cartoon illustrations were drawn by Brett Hansen.

The Leukaemia Foundation values feedback from patients, their families, carers and health care professionals working with people with blood disorders. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact the General Manager, Support Services at [info@leukaemia.org.au](mailto:info@leukaemia.org.au).

**October 2011**



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# INTRODUCTION

This booklet has been written to help you and your family to understand more about Hodgkin lymphoma (also known as Hodgkin's disease).

Some of you may be feeling anxious or a little overwhelmed if you or someone you care for has been diagnosed with Hodgkin lymphoma. This is normal. Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor, or specialist nurse.

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be of most use at a particular point in time.

We have used some medical words and terms which you may not be familiar with. These are highlighted in *italics*. Their meaning is explained in the booklet and / or in the glossary of terms at the back of the booklet.

In some parts of the booklet we have provided additional information you may wish to read on selected topics. This information is presented in the shaded boxes. Some of you may require more information than is contained in this booklet. We have included some internet addresses that you might find useful. In addition, many of you will receive written information from the doctors and nurses at your treating hospital.

It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your particular circumstances at all times with your treating doctor and team.

Finally, we hope that you find this booklet useful and we would appreciate any feedback from you so that we can continue to serve you and your families better in the future.

## THE LEUKAEMIA FOUNDATION

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders. Since 1975, the Foundation has been committed to improving survival for patients and providing much needed support. The Foundation does not receive direct ongoing government funding, relying instead on the continued and generous support of individuals and corporate supporters to develop and expand its services.

The Foundation provides a range of **free** support services to patients and their carers, family and friends. This support may be offered over the telephone, face to face at home, hospital or at the Foundation's office or accommodation centres, depending on the location and individual needs. The Foundation provides practical and emotional assistance to patients and carers, including access to information, education and peer support through a variety of programs.

The Leukaemia Foundation funds leading research into better treatments and cures for leukaemias, lymphomas, myeloma and related blood disorders. Through its National Research Program, the Foundation has established the Leukaemia and Lymphoma Tissue Bank at the Princess Alexandra Hospital, Queensland and the Leukaemia Foundation Research Laboratory at the Queensland Institute for Medical Research. In addition, the Foundation also funds research grants, scholarships and fellowships for talented researchers and health professionals.

The Leukaemia Foundation has a close relationship and supports the Australasian Leukaemia and Lymphoma Group (ALLG), the multi-centre co-operative group of institutions in Australia and New Zealand which carries out important clinical research in the treatment of haematological cancers, including Hodgkin lymphoma.

## Support Services



*"Foundation staff provide patients and their families with information and support across Australia"*

The Leukaemia Foundation has a team of highly trained and caring Support Services staff with qualifications in nursing or allied health that work across the country. They can offer individual support and care to you and your family when it is needed.

Support Services may include:

### ***Information***

The Leukaemia Foundation has a range of booklets, fact sheets, DVDs and other resources that are available free of charge. These can be ordered via the form at the back of this booklet or downloaded from the website. Translated versions (in languages other than English) of some booklets and fact sheets are also available from our website.

### ***Education & support programs***

The Leukaemia Foundation offers you and your family Hodgkin lymphoma-specific as well as general education and support programs throughout Australia. These programs are designed to empower you with information about various aspects of diagnosis and treatment, and how to support your general health and well being.

## ***Emotional support***

A diagnosis of Hodgkin lymphoma can have a dramatic impact on a person's life. At times it can be difficult to cope with the emotional stress involved. The Leukaemia Foundation's Support Services staff can provide you and your family with much needed support during this time. They may refer you or a loved one to a specialist health professional e.g. a psychologist, if required.

## ***Online discussion forum***

The Foundation has established an on-line information and support group for people living with *leukaemia*, *lymphoma*, *myeloma*, or a related blood disorder. Registration is free and participants can remain anonymous, see [www.talkbloodcancer.com](http://www.talkbloodcancer.com)

## ***Telephone discussion forum***

These forums enable people across the country who have been affected by lymphoma to share their experiences, provide tips, education and support to others in a relaxed forum. Each forum is facilitated by a member of the Leukaemia Foundation's Support Services team who has a background in haematology nursing. A bone marrow transplant forum is also available.

## ***Accommodation***

Some patients and carers need to relocate for treatment and may need help with accommodation. The Leukaemia Foundation staff can help you to find suitable accommodation close to your hospital or treatment centre. In many areas, the Foundation's fully furnished self-contained units and houses can provide a 'home away from home' for you and your family.

## ***Transport***

The Foundation also assists with transporting patients and carers to and from hospital for treatment. Courtesy cars and other services are available in many areas throughout the country.

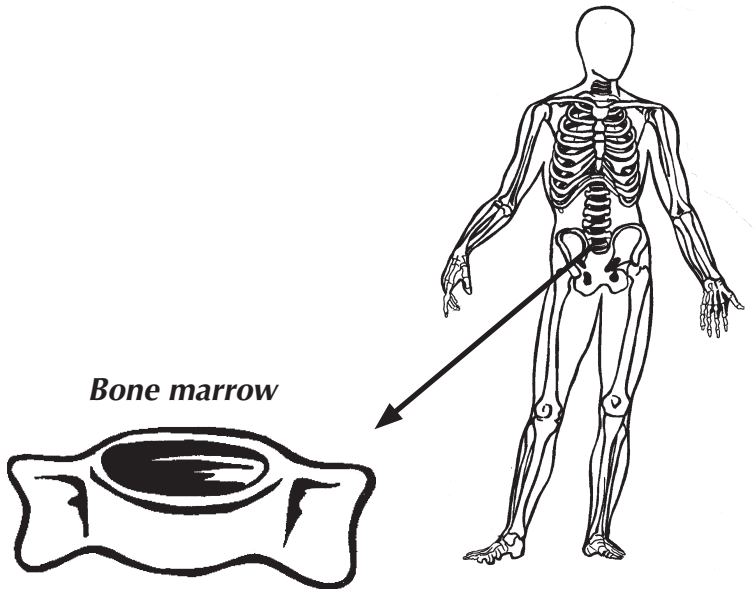
## ***Practical assistance***

The urgency and lengthy duration of medical treatment can affect you and your family's normal way of life and there may be practical things the Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for patients who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

## ***Contacting us***

The Leukaemia Foundation provides services and support in every Australian state and territory. Every person's experience of living with Hodgkin lymphoma is different. Living with Hodgkin lymphoma is not easy, but you don't have to do it alone. Please call **1800 620 420** (Freecall) to speak to a local support service staff member or to find out more about the services offered by the Foundation. Alternatively, contact us via email by sending a message to [info@leukaemia.org.au](mailto:info@leukaemia.org.au) or visit [www.leukaemia.org.au](http://www.leukaemia.org.au)

# GETTING TO KNOW YOUR BONE MARROW, STEM CELLS AND BLOOD



## Bone marrow

*Bone marrow* is the spongy tissue that fills the cavities inside your bones. Most of your blood cells are made in your bone marrow. The process by which blood cells are made is called *haemopoiesis*.

As an infant, haemopoiesis takes place at the centre of all bones. In later life, it is limited to the hips, pelvis, ribs, spine, skull and breastbone (sternum). Some of you may have had a bone marrow biopsy taken from the bone at the back of your hip (the iliac crest) or the breastbone.

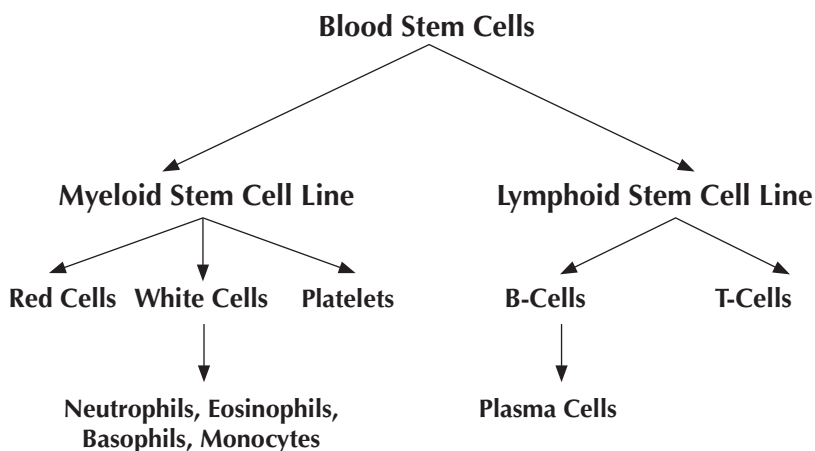
You might like to think of the bone marrow as the blood cell factory. The main workers at the factory are the blood *stem cells*. They are relatively small in number but are able, when stimulated, to reproduce vital numbers of red cells, *white cells* and platelets. All blood cells need to be replaced as they have a limited life span.

There are two main families of stem cells, which develop into various types of blood cells.

*Myeloid ('my-loid') stem cells develop into red cells, white cells (neutrophils, eosinophils, basophils and monocytes) and platelets.*

*Lymphoid ('lim-foid') stem cells develop into two other types of white cells called T-cells and B-cells.*

## Growth factors and cytokines

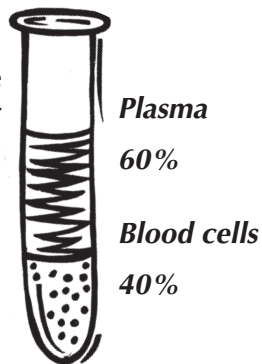


All normal blood cells have a limited survival in circulation and need to be replaced on a continual basis. This means that the bone marrow remains a very active tissue throughout your life. Natural chemicals in your blood called *growth factors* or *cytokines* control the process of blood cell formation. Different growth factors stimulate the blood stem cells in the bone marrow to produce different types of blood cells.

These days some growth factors can be made in the laboratory (synthesised) and are commercially available for use in people with blood disorders. For example, *granulocyte colony-stimulating factor* (G-CSF) stimulates the production of white cells called *neutrophils* while *erythropoietin* (EPO) stimulates the production of red cells.

## Blood

Blood consists of blood cells and *plasma*. Plasma is the straw-coloured fluid part of the blood that blood cells use to travel around your body and contains many important proteins, such as clotting factors.



## Blood Cells

### *Red cells and haemoglobin*

Red cells contain *haemoglobin* (Hb), which gives the blood its red colour and transports oxygen from the lungs to all parts of the body. The body needs this oxygen to create energy and for the organs to perform their functions.

*The normal haemoglobin (Hb) range for a man is approximately 130 - 170 g/L*

*The normal haemoglobin range for a woman is approximately 120 - 160 g/L*

Red cells are by far the most numerous blood cell and the proportion of the blood that is occupied by red blood cells is called the *haematocrit*. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

*The normal range of the haematocrit (HCT) in a man is between 40% and 52%*

*The normal range of the haematocrit in a woman is between 36% and 46%*

**FACT:** Did you know that you produce around 2 million red blood cells every second.

## **Anaemia**

*Anaemia* is a condition caused by a reduction in the number of red cells or low haemoglobin. Measuring either the haematocrit or the haemoglobin will provide information regarding the degree of anaemia.

If you are anaemic you will feel run down and weak. You may be pale and short of breath or you may tire easily because your body is not getting enough oxygen. In this situation a red cell transfusion (blood transfusion) may be given to restore the red cell numbers, and therefore the haemoglobin, to more normal levels.

***Low haemoglobin = Low oxygen = Low energy***

### ***White cells***

White cells, also known as *leukocytes*, fight infection. There are different types of white cells that fight infection together and in different ways.

#### ***Myeloid Cell Lines***

*Neutrophils*      kill bacteria and fungi

*Eosinophils*    kill parasites

*Basophils*        work with neutrophils to fight infection

*Monocytes*      work with neutrophils and *lymphocytes* to fight infection; they also help with antibody production and act as scavengers to remove dead tissue. These cells are known as *monocytes* when they are found in the blood and *macrophages* when they migrate into body tissues to help fight infection.

#### ***Lymphoid Cell Lines***

*T-cells*            kill viruses, parasites and *cancer* cells; produce cytokines

*B-cells*            make *antibodies* which target *pathogens*, particularly *bacteria*

When your white cell count drops below normal you are at risk of infection.

*The normal adult white cell count varies between 3.7 and 11 x 10<sup>9</sup>/L*

## **Neutropenia**

*Neutropenia* is the term used to describe a lower than normal neutrophil count. If you have a neutrophil count of less than  $1 (1 \times 10^9/L)$  you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections.

*The normal adult neutrophil count varies between 2.0 and  $7.5 \times 10^9/L$*

## **Platelets**

Platelets are disc-shaped cellular fragments that circulate in the blood and play an important role in clot formation. They help to prevent bleeding. If a blood vessel is damaged (e.g. by a cut) the platelets gather at the site of injury, stick together and form a plug to help stop the bleeding, and release chemicals to contribute to blood clotting.

*The normal adult platelet count varies between 150 and  $400 \times 10^9/L$*

## **Thrombocytopenia**

Thrombocytopenia is the term used to describe a reduction in the platelet count to below normal. If your platelet count drops below 20 ( $20 \times 10^9/L$ ) you are at risk of bleeding and tend to bruise easily. Platelet transfusions are sometimes given to bring the platelet count back to a safe level.

The normal *blood counts* provided here may differ slightly from the ones used at your treatment centre. You can ask for a copy of your blood results, which should include the normal values for each cell type.

## Children

In children, some normal blood cell counts vary with age (see table below).

If your child is being treated for Hodgkin lymphoma you can ask your doctor or nurse for a copy of their blood results, which should include the normal values for each blood type for a male or female child of the same age.

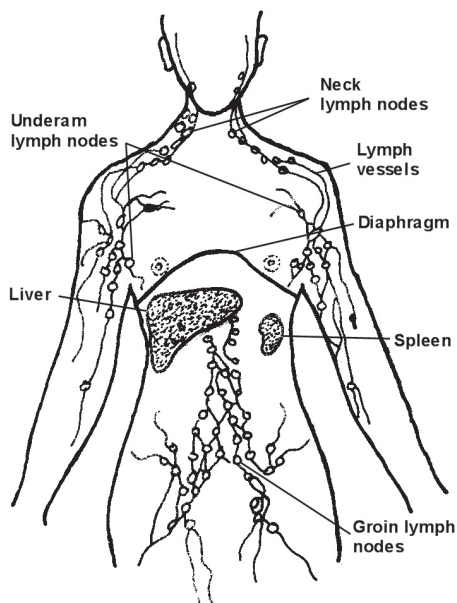
|  | <b>1 month</b> | <b>1 year</b> | <b>3 years</b> | <b>5 years</b> | <b>9 years</b> |
|--|----------------|---------------|----------------|----------------|----------------|
| Haemoglobin g/L                        | 102-130        | 104-132       | 107-137        | 110-139        | 113-143        |
| White cell count<br>$\times 10^{12}/L$ | 6.4-12.1       | 5.4-13.6      | 4.9-12.8       | 4.7-12.3       | 4.7-12.2       |
| Platelets $\times 10^{12}/L$           | 270-645        | 205-553       | 214-483        | 205-457        | 187-415        |
| Neutrophils                            | 0.8-4.9        | 1.1-6.0       | 1.7-6.7        | 1.8-7.7        | 1.8-7.6        |

## THE LYMPHATIC SYSTEM

The *lymphatic system* is made up of a vast network of lymph vessels, similar to blood vessels that branch out into all the tissues of the body. The two main roles of the lymphatic system are: to drain excess fluid from the body's tissues, filter it and return it to the blood stream; and to harbour specialist white blood cells – lymphocytes – to help fight infection.

There are two types of lymphocytes, *B-lymphocytes* and *T-lymphocytes* (also called B-cells and T-cells). These cells protect us by destroying harmful microorganisms such as bacteria and viruses. As such, the lymphatic system forms part of the *immune system*, which protects our bodies against disease and infection.

Clusters of small bean-shaped organs called *lymph nodes* (also known as lymph glands) are found at various points throughout the lymphatic system. The lymph nodes, which are filled with B-cells and T-Cells, act as important filtering stations, cleaning the lymph fluid as it passes through them. Here bacteria, viruses and other harmful substances are removed and destroyed. When you have an infection, for example a sore throat, you may notice that the lymph nodes under your jaw bone become swollen and tender. This is because the B-cells and T-Cells which live there become activated and multiply in response to the virus or bacteria causing the infection.



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 (spongy material inside bones) all contain lymphatic tissue and are therefore considered to be part of the lymphatic system. Lymphatic tissue is also found in the stomach, gut and skin.

## WHAT IS LYMPHOMA?

*Lymphoma* is the general term for cancers that develop in the *lymphatic system*. There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma. There are 43 different types of lymphoma currently recognised by the World Health Organisation's classification system. Five of these are different types of Hodgkin lymphoma.

Lymphomas originate in developing B-cells and T-cells, which have undergone a *malignant* (cancerous) change. This means that they multiply without any proper order forming *tumours*, which are collections of cancer cells. These tumours cause swelling in the lymph nodes and other parts of the body. Over time, malignant lymphocytes (called lymphoma cells) crowd out normal lymphocytes. Eventually, the immune system becomes weakened and can no longer function properly.

## WHAT IS HODGKIN LYMPHOMA?

Hodgkin lymphoma is distinguished from all other types of lymphoma because of the presence, under the microscope, of a special kind of cancer cell called a *Reed-Sternberg cell*. When it is first diagnosed, Hodgkin lymphoma may affect a single lymph node or a group of lymph nodes or it may affect another part of the body 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.

With treatment, most people with Hodgkin lymphoma can be *cured*; this is especially true for younger patients who are diagnosed with early-stage disease. Advanced stage Hodgkin lymphoma can also be treated very successfully and cured in a high proportion of patients.

### ***Who gets it?***

Hodgkin lymphoma can occur at any age but it is most common in adolescents and young adults with over a third of all cases diagnosed between the ages of 15 and 30 years. Around 30 children (0-14 years) are diagnosed with Hodgkin lymphoma each year.

### ***How common is it?***

Hodgkin lymphoma is a relatively rare disease. It accounts for around 0.5 per cent of all cancers and 10 per cent of all lymphomas diagnosed. Each year in Australia, around 600 people are diagnosed with Hodgkin lymphoma. Hodgkin lymphoma occurs more frequently in males than in females.

## **WHAT CAUSES HODGKIN LYMPHOMA?**

Many people who are diagnosed with lymphoma ask the question “why me? “ Naturally, they want to know what has happened or what they might have done to cause their disease. The truth is that no one knows exactly what causes Hodgkin lymphoma. We do know that it is not contagious. You cannot ‘catch’ Hodgkin lymphoma by being in contact with someone who has it. Like many cancers, damage to special proteins which normally control the growth and division of cells may play a role in its development.

There is some evidence to suggest that people are more at risk of developing Hodgkin lymphoma if their immune system has been weakened either by a viral infection such as human immunodeficiency virus (HIV) or as a result of the use of drugs which affect the function of the immune system (*immune suppressants*). These drugs are commonly used when someone has a heart, lung or other organ transplant. Infection with Epstein-Barr virus (EBV), the virus that causes glandular fever, *may* put some people at a higher risk of developing Hodgkin lymphoma.

In most cases, people who are diagnosed with Hodgkin lymphoma have no family history of the disease. There have been some cases however, where a brother or sister also develops Hodgkin lymphoma, suggesting a rare family genetic link to the disease. As this is very rare, it is not recommended that families undergo testing for the disease when a family member is diagnosed with Hodgkin lymphoma.

## WHAT ARE THE SYMPTOMS OF HODGKIN LYMPHOMA?

Some people do not have any symptoms when they are first diagnosed with Hodgkin lymphoma. In these cases the disease may be diagnosed whilst undergoing medical tests for completely different reasons – such as wanting to travel, or commence a new job.

In others, Hodgkin lymphoma usually presents as a firm, painless swelling of a lymph node (swollen glands), usually in the neck, under the arms or in the groin. It is important to remember that most people who go to their doctor with enlarged lymph nodes do not have Hodgkin lymphoma. Swollen glands often result from an infection, for example a sore throat. In this case the glands in the neck are usually swollen and painful.

Other symptoms may include:

- recurrent fevers
- excessive sweating at night
- unintentional weight loss
- persistent fatigue and lack of energy
- generalised itching or a rash
- dizziness

These symptoms are also seen in other illnesses such as viral infections. Most people with these complaints do not have Hodgkin lymphoma. However, it is important to see your doctor if you have any symptoms that do not go away so that you can be examined and treated properly and in a timely fashion.

## WHICH DOCTOR?

If your general practitioner (GP) suspects that you might have Hodgkin lymphoma you will be referred on to other specialist doctors for further tests and treatment. These may include the following:

*Haematologist*: a doctor who specialises in the care of people with diseases of the blood, bone marrow and immune system.

*Oncologist*: a doctor who specialises in the treatment of cancer. A *medical oncologist* specialises in *chemotherapy*, and a *radiation oncologist* specialises in *radiotherapy*.



## HOW IS HODGKIN LYMPHOMA DIAGNOSED?

When you see your doctor, the first thing he or she will do is give you a full physical examination. The doctor will look and feel for any swelling of the glands in your neck, armpits and groin. Your abdomen and chest will also be examined for any signs of swollen organs or fluid collection. The doctor will also ask you about any other symptoms you might have.

At this stage some blood samples may be taken to check how well your bone marrow, liver and kidneys are functioning.

## Biopsy

If the doctor suspects that you might have Hodgkin lymphoma, a biopsy will need to be done to help confirm the diagnosis. A biopsy involves removing a lymph node or a sample of tissue from a suspicious lump, which is then examined in the laboratory.

There are different types of biopsies. A *core* or *fine needle* biopsy involves inserting a needle into a lymph node or lump and removing a sample of tissue. This is usually done under local anaesthetic, while you are awake. If the affected lymph node is deep inside the body, the biopsy may be done with the help of *ultrasound* or specialised x-ray (imaging) guidance.

A *surgical* or *excision* biopsy involves removing the entire swollen lymph node. You will usually need a general anaesthetic for this and you will have a few stitches afterwards.

If the swollen gland is in your abdomen or pelvis, a *laparoscopy* may be done to get a sample of the lymphatic tissue involved. A laparoscopy is a surgical procedure in which a narrow tube with a tiny microscope attached is inserted through a small cut in the skin. It allows the surgeon to see the inside of your abdomen or pelvis, and to take a biopsy if needed. This is done under general anaesthetic and you will have a few stitches afterwards.

Once the tissue samples are removed, they are examined in the laboratory by a *pathologist*. A pathologist is a doctor who is specially trained to examine tissue specimens and cells, to help diagnose diseases like cancer.

It can take a few days for the final results of the biopsy to come through. This is because the doctors take great care to make an accurate diagnosis. An accurate diagnosis of the exact type of disease you have is important because this helps your doctor decide on the very best treatment for you.

*Understandably, waiting for results can be a very distressing time for you and your family. It may help to talk about your feelings with someone you are close to or feel comfortable with.*

## TYPES OF HODGKIN LYMPHOMA

There are currently five different sub-types of Hodgkin lymphoma recognised by the latest World Health Organization's classification system. In simple terms, the different sub-types are distinguished from each other by the appearance of the cells under the microscope.

### ***Types of Hodgkin lymphoma***

#### ***Nodular sclerosing***

- most common subtype
- more commonly seen in young adults
- usually involves the lymph glands of the neck and chest

#### ***Mixed cellularity***

- more commonly seen in older people (over 50 years)
- type most often associated with Epstein-Barr virus (EBV)

#### ***Lymphocyte-rich***

- a rare subtype with the most favourable outcome
- Very few Reed-Sternberg cells making it challenging to diagnose correctly

#### ***Lymphocyte depleted***

- disease tends to be more widespread at diagnosis

#### ***Nodular lymphocyte predominant***


- tends to be slow growing
- responds well to radiotherapy and chemotherapy

*Most patients have a good response to treatment regardless of the type of Hodgkin lymphoma they have. A more important consideration in the choice of treatment is how widely the lymphoma has spread in your body.*


## Staging

The extent to which the lymphoma has spread in your body is called the stage of the disease. In stages 1 and 2, lymphoma is limited to one or two areas of the body (early stage). In stages 3 and 4, the disease is more widespread in the body (advanced stage).


**Stages of lymphoma**




**Stage 1**  
*lymphoma is limited to one group of lymph nodes or one organ/area outside the lymph nodes*



**Stage 2**  
*lymphoma is limited to two groups of lymph nodes or organ/area outside the lymph nodes either above or below the diaphragm (the large muscle that separates the stomach and the chest)*



**Stage 3**  
*lymphoma is found in lymph nodes and/or an organ or other area both above and below the diaphragm*



**Stage 4**  
*lymphoma has spread outside the lymph nodes to one or more organs, for example; the bone marrow, lungs, liver and skin*

### **A, B or E?**

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' is used when lymphoma has spread to an area or organ outside the lymph nodes, for example 4E.

## Staging tests

Once a diagnosis of lymphoma is made, further tests need to be done to find out the extent to which the disease has spread in your body and the effect it is having on important body organs. This information will help your doctor to decide on the best treatment for you.

### Diagnostic and staging tests

- Biopsy
- Blood tests
- Imaging tests
  - x-rays
  - CT (computerized tomography) scans of the chest, abdomen and pelvis
  - MRI (magnetic resonance imaging)
  - gallium scan
  - PET (positron emission tomography)
- Bone marrow examination

### ***Blood tests***

Blood tests provide important information on how well your bone marrow, liver and kidneys are functioning. These tests provide a baseline set of results regarding your disease and general health. They can then be compared with later results to see how well you are responding to your treatment.

### ***Computerised axial tomography (CT scan or CAT scan)***

CT scans provide computer analysed, three dimensional (3D) images of cross sections of your body. This technology is able to detect tiny changes in tissue density which might indicate the presence of an infection or a tumour. The CT scan does not hurt and it usually takes less than an hour to complete. While the scan is being done you have to lie flat and still on a cushioned table that moves slowly through the CT machine. The machine itself looks like a giant ring surrounding the table. Sometimes a special dye

(called a contrast) is used to enhance the quality of the pictures taken. The contrast may be either swallowed or injected into a vein in your hand or arm before the scan. The CT scanner displays the contrast as it moves through the body, highlighting areas to be examined more closely.

CT scans of chest, abdomen and pelvis are often used to assess the spread of lymphoma in the body.

The CT scan may make some people feel claustrophobic, speak with your doctor if you feel you may experience this. Your doctor may offer you a relaxant.

### ***Magnetic resonance imaging (MRI)***

MRI is another body scanning technique. It uses a very strong magnet and radio waves to produce very clear and detailed three dimensional (3D) images of the body. An MRI may be done when the doctor needs a very clear picture of the brain and spinal cord to see if these areas are affected by cancer.

MRI is painless and usually takes about an hour to complete. The MRI scan may make some people feel claustrophobic, speak with your doctor if you feel you may experience this. Your doctor may offer you a relaxant.

### ***Gallium scan***

A *gallium scan* is another imaging technique which involves the use of radioactive gallium (a type of metal in a liquid form). The gallium is injected into a vein in your hand or arm, in the nuclear medicine department of the hospital. You then leave the nuclear medicine department and return 24 to 48 hours later. By this time, the gallium has travelled through your body and you are scanned from several different angles to examine where the gallium has collected, indicating deposits of lymphoma. Gallium is not harmful and the gallium scan itself is painless.

### ***Positron emission tomography (PET) scan***

PET scanning uses radioactive glucose which is injected into a vein in your hand or arm. Special *gamma* cameras are used to trace the glucose as it moves through your body and detect areas affected by lymphoma. Using this technology, slow growing lymphomas can be distinguished from fast growing ones because of the rate at which the glucose is used by the different cells.

PET scans give a very accurate picture of the actual stage of your lymphoma and are also used during treatment to determine your response.

### ***Bone marrow examination***

A bone marrow examination (biopsy) involves taking a sample of bone marrow, usually from the back of your iliac crest (hip bone) to see if there are any lymphoma cells present, and to see how well your bone marrow is functioning.

#### ***Bone Marrow Examination***

The bone marrow examination is usually done in a day procedure unit under local anaesthesia or, in selected cases, under a short general anaesthetic. A mild sedative and a pain-killer is given beforehand and the skin is numbed using a local anaesthetic; this is given as an injection under the skin. The injection takes a minute or two, and you should feel only a mild stinging sensation. After allowing time for the local anaesthetic to work, a long thin needle is inserted through the skin and outer layer of bone into the bone marrow cavity. A syringe is attached to the end of the needle and a small sample of bone marrow fluid is drawn out - this is called a bone marrow aspirate. A slightly larger needle may then be used to obtain a small core of bone marrow which will provide more detailed information about the structure of the bone marrow and bone - this is known as a bone marrow trephine.

Because you might feel a bit drowsy afterwards and the sedation can affect how you think, you should be accompanied by a family member or friend who can take you home. A small dressing or plaster will be placed over the biopsy site and this can be removed the next day. There may be some mild bruising or discomfort, which is usually managed effectively by paracetamol. More serious complications such as bleeding or infection are very rare.

*Waiting around for tests can be both stressful and boring. Remember to ask beforehand how long the test will take and what to expect afterwards. You might like to bring a book, some music, or a friend for company and support.*

### **Other tests**

Other tests may be used to assess your general health and the function of various organs. These tests include:

- chest x-ray
- electrocardiogram (ECG)
- heart scan - either nuclear medicine scan or echocardiogram
- lung function tests
- 24-hour urine collection

### **Prognosis**

A *prognosis* is an estimate of the likely course of your disease. It provides some guide regarding the chances of curing your disease or controlling it for a given time and assists the doctor in deciding which therapy is best for the disease that you have.

*Your doctor is the best person to give you an accurate prognosis regarding your lymphoma as he or she has the most information to make this assessment.*

Your doctor will generally tell you the chance or percentage of achieving a remission or cure. This means, that if 100 people with similar stage and other factors to yours were treated, your doctor will tell you how many of those people would be cured.

When given a prognosis, it is important to remember that you are an individual and not a statistic. Statistics do not determine what will happen to you in your particular circumstance. How you respond to treatment will not be known until you have had the therapy.

The majority of people treated for Hodgkin lymphoma can be cured. Many others who are treated remain disease-free and well for a long time. This is also known as being in *remission*. If Hodgkin lymphoma comes back or *relapses* more treatment may be required to get you well again and back into remission .

### ***Commonly used prognostic terms***

#### ***Cure***

This means that there is no evidence of lymphoma and no sign of it reappearing even after many years (usually five years). With effective treatment, the majority of people with Hodgkin lymphoma can be cured of their disease.

#### ***Complete remission***

This means that the treatment has been successful and that 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 may reappear, even after a long time. Because of this, regular checkups are necessary while you are in remission.

#### ***Partial remission***

This term is used when the lymphoma shrinks to less than half its original size following treatment, but there is still some disease remaining in the body.

#### ***Stable disease***

When the lymphoma is stable and is not getting any better or worse with treatment.

#### ***Relapse***

The lymphoma has reappeared after a period of remission.

#### ***Resistant or refractory disease***

This means that the lymphoma is not responding to treatment.

#### ***Disease progression***

Where the lymphoma is getting worse, on or off treatment.

## TREATMENT

The treatment recommended for your Hodgkin lymphoma will depend mainly on the stage of your disease. Other factors will also be considered including your age and general health.

Treatment usually involves chemotherapy or radiotherapy or a combination of both. In selected cases, a *stem cell transplant* (also called a *peripheral blood stem cell* or *bone marrow transplant*) may be performed.

Information gathered from treating hundreds of other people around the world who have had the same disease helps to guide the doctor in recommending the best treatment for you. **Remember however that no two people are the same.** In helping you to make the best treatment decision, your doctor will consider all the information available including the details of *your* particular situation.

### Early-stage disease

The great majority of people with early stage Hodgkin lymphoma (stages 1 and 2) are cured. There are often several options available for your treatment which your doctor should discuss with you. Early-stage disease is usually treated with a combination of chemotherapy and radiotherapy. Typically, you may receive 3-4 months of chemotherapy followed by a course of radiotherapy. In some patients, chemotherapy alone is used for up to 6 months. The decision regarding which of these options should be used will depend on your disease stage and which side effects of treatment are important to you.

### Advanced-stage disease

Advanced-stage disease (stages 3 and 4) is usually treated with a longer course of chemotherapy. In most patients, the chemotherapy will continue for 6 months or even longer. Occasionally radiotherapy is also used.

## Relapsed and resistant disease

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 or using more and different chemotherapy or using more intensive or *high-dose* chemotherapy followed by a stem cell transplant (*see below*).

## Standard therapy

*Standard therapy* refers to types of treatment which are commonly used. These treatments have been tried and tested both in clinical trials and through long-term clinical use, and have been proven to be effective and reasonably safe.

## Chemotherapy

Chemotherapy literally means 'therapy with chemicals'. Many chemotherapy drugs are also called cytotoxics (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells.

Chemotherapy usually involves a combination of drugs (combination chemotherapy). The names of different combinations of drugs are commonly derived from the first letters of each of the drugs used. For example the combination **ABVD** (**A**driamycin, **B**leomycin, **V**inblastine and **D**acarbazine) is commonly used to treat Hodgkin lymphoma. Another called **BEACOPP** involves a combination of the drugs **B**leomycin, **E**toposide, **A**driamycin, **C**yclophosphamide, **P**rocarbazine and **P**rednisone. Each drug targets the cancer in a different way. A combination of chemotherapy drugs has been proven to be more effective than a single drug in destroying the lymphoma.

A course of chemotherapy for Hodgkin lymphoma is usually given in several *cycles* (or courses) with a rest period of a few (usually 2 or 3) weeks in between each cycle. This is to allow the body to recover from the side-effects of chemotherapy. A typical chemotherapy regime for Hodgkin lymphoma might involve around six to eight cycles of a combination of drugs, given over a period of several months.

### How is chemotherapy given?

There are many different ways of giving chemotherapy. It may be given through a vein (intravenously or IV), usually in your arm or hand, or in tablet form (orally).



If you are having several cycles of intravenous chemotherapy your doctor may recommend that you have a *central venous catheter* (also called a central line) inserted. A central venous catheter is a special line inserted through the skin, into a large vein in your arm, neck or chest. Once in place, chemotherapy and any other IV drugs can be given through the line and blood tests can usually be taken from the line, without the need for frequent needle pricks.

There are several different kinds of central lines used; some are intended for short-term use while others remain in place for months and even years. You may like to discuss with your doctor where these lines are placed on your body, to minimise the visibility of long-term scarring. These lines require special care to prevent infection. If necessary, the nurses at your treatment centre will teach you how to look after your line.

In most cases you do not need to be admitted into a hospital ward for overnight stay for chemotherapy for Hodgkin lymphoma as it is usually given in the outpatients' department of the hospital. Sometimes however, depending on the type of chemotherapy being given and your general health, you may need to be admitted to the ward for a short while.

## **What happens during chemotherapy?**

You will have to attend the hospital or the chemotherapy day centre for your chemotherapy. How frequently that is necessary will depend on the type of chemotherapy which you are receiving.

Your doctor will want to see you fairly frequently during your chemotherapy. You will need blood tests between chemotherapy cycles and also 1-2 days prior to each treatment to make sure that your blood count has recovered from the previous cycle.

Your doctor will order some x-rays and scans at the end of your chemotherapy and sometimes also after 2-3 cycles. This is to tell how well you are responding to the chemotherapy and whether you should continue with the same treatment or change.

## Side-effects of chemotherapy

Chemotherapy kills cells that multiply quickly, such as cancer cells. It also causes damage to fast-growing *normal* cells, especially hair cells, and cells in your mouth, gut and bone marrow. Other cells are also affected. The side-effects of chemotherapy occur as a result of damage to these normal cells.

The type of side-effects and their severity varies from person to person depending on the type of chemotherapy used, and how an individual responds to it. There is no doubt that side-effects can be very unpleasant at times but it's helpful to remember that most of them are temporary and reversible. It is important that you report any side-effects you are experiencing to your nurse or doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you.

### ***Effects on the bone marrow***

As we mentioned previously, all your white cells, platelets and red cells are made in your bone marrow. Chemotherapy temporarily affects the bone marrow's ability to produce adequate numbers of these cells. As a result, your blood count (the number of red cells, white cells and platelets circulating in your blood) will generally fall within a couple of weeks of treatment. The length of time it takes for your bone marrow and blood counts to fall and recover mainly depends on the type of chemotherapy given.

### ***White cells***

The point at which your white cell count is at its lowest is called the *nadir*. This is usually expected 10 to 14 days after having your chemotherapy. During this time you will be at a higher risk of developing an infection. A blood test will be arranged for you during this time to check your blood count. At this stage you may also be *neutropenic*, which means that your neutrophil count is low. Neutrophils are important white blood cells that help us to fight infection.

While your white blood cell count is low you should take sensible precautions to help prevent infection. These include avoiding crowds, as much as possible, avoiding close contact with people with infections which are contagious (for example colds, flu, chicken pox) and only eating food which has been properly prepared and cooked (low bacterial). Reheated food, raw fish and other raw seafood, soft cheeses and salad bars should be avoided. Your doctor and nurse will advise you on how to reduce your risk of infection while your white cell count is low.

Sometimes your doctor may decide to use a drug like G-CSF to help the recovery of your neutrophil count. This drug works by stimulating the bone marrow to increase the production of neutrophils. G-CSF is given as an injection under the skin (subcutaneous). This is quite a simple procedure and the nurses can usually teach you or a family member (or friend) to do this at home.

If you do develop an infection you may experience a fever which may or may not be accompanied by an episode of shivering. This shivering is known as a *rigor* and is characterised by uncontrollable shaking. Infections while you are neutropenic may be very serious and need to be treated with antibiotics as soon as possible.

### ***Platelets***

Your platelet count may also be affected by the chemotherapy you are receiving, and you may become *thrombocytopenic* (a reduction in the number of platelets circulating in your blood). If your platelet count is very low you can bruise and bleed more easily. During this time it is helpful to avoid sharp objects in your mouth such as chop bones or potato chips, as these can cut your gums. Using a soft toothbrush also helps to protect your gums. If necessary, your doctor will prescribe a platelet transfusion to reduce the risk of bleeding until the platelet count recovers.

### ***Red cells***

If your red blood cell count and haemoglobin levels drop below normal levels, you will be *anaemic*. When you are anaemic you feel more tired and lethargic than usual. If your haemoglobin level is very low, your doctor may prescribe a blood transfusion.

# WHEN SHOULD I CONTACT MY DOCTOR?

It is important that you contact your doctor or the nursing team for advice immediately (at any time of the day or night) if you are feeling very unwell, or if you experience **any** of the following:

- **a temperature of 38°C or higher\*** (even if it returns to normal) and/or an episode of uncontrolled shivering (also called a rigor)
- **bleeding or bruising**, for example blood in the urine and/or bowel motions; coughing up blood, bleeding gums or a persistent nose bleed
- **nausea or vomiting that is prolonged** and prevents you from eating or drinking or taking your normal medications
- **diarrhoea, stomach cramps or severe constipation**
- **persistent coughing or shortness of breath**
- **the presence of a new rash, reddening and/or itching of the skin**
- **a persistent headache**
- **a new severe pain or persistent unexplained soreness**
- **a cut or other injury**
- **persistent pain, swelling, redness or pus** anywhere on your body

**\*The normal body temperature is between 36 and 37°C**

## ***Nausea and vomiting***

Nausea and vomiting are often associated with chemotherapy and some forms of radiotherapy. These days however, thanks to significant improvements in anti-sickness (*anti-emetic*) drugs, nausea and vomiting are generally very well controlled. You will be given anti-sickness drugs before your treatment, and for a few days after each treatment cycle. Be sure to tell the nurses and doctors if the anti-emetics are not working for you and you still feel sick. There are many different types of anti-emetics that can be tried. A mild sedative may also be used to help stop you feeling sick. This will help you to relax but it might make you a little sleepy.

Some people find that eating smaller meals more frequently during the day, rather than a few large meals, helps to reduce nausea and vomiting. Many find that eating cool or cold food is more palatable, for example jelly or custard. Drinking ginger ale or soda water and eating dry toast may also help if you are feeling sick. Getting plenty of fresh air, avoiding strong or offensive smells, and taking the prescribed anti-sickness drugs as recommended by the nurse and doctor should also help.

### ***Changes in taste and smell\****

Both chemotherapy and radiotherapy can cause changes to your sense of taste and smell. This is usually temporary but in some cases it lasts up to several months. During this time you may not be able to enjoy the foods and drinks that you used to love and this can be very disappointing, but it will pass. Some people find that adding a little more sugar to sweet foods and salt to savoury foods can help.

### ***Mucositis***

*Mucositis* is an inflammation of the lining of the mouth, throat or gut and is a common and uncomfortable side-effect of chemotherapy, and some forms of radiotherapy. It usually starts about a week after the treatment has finished and goes away once your blood count recovers (usually a couple of weeks later). During this time your mouth and throat could get quite sore. Soluble paracetamol and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe, stronger pain killers might be needed. Ask your doctor or nurse for help if mucositis is bothering you.

It is important to keep your mouth as clean as possible while you are having treatment to help prevent infection. It is particularly important to perform *mouth care* regularly while your mouth is sore. Your nurse will show you how to care for your mouth during this time. This may include using a soft toothbrush and mild toothpaste. Avoid commercial mouthwashes, like the ones you can buy at the supermarket. These are often too strong, or they may contain alcohol which will hurt your mouth.

Some people believe that sucking on ice or an ice block during the administration of chemotherapy can help to reduce the incidence of mouth ulcers – ask your treatment centre about this option.

*\*There is a separate Leukaemia Foundation booklet called 'Eating Well'*

Occasionally mouth pain or mouth ulcers may develop as a result of infection e.g. thrush (*Candida albicans*), cold sores (*Herpes simplex*). These need specific treatment which will be prescribed by your doctor.

### **Bowel changes**

Chemotherapy can cause damage to the lining of your bowel wall. This can lead to cramping, wind, abdominal swelling and constipation or diarrhoea. Be sure to tell the nurses and doctors if you experience any of these symptoms. If you develop diarrhoea, a specimen will be required from you to ensure that the diarrhoea is not the result of an infection. After this you will be given some medication to help stop the diarrhoea and/or the discomfort you may be feeling.

It is also important to tell the nurse or doctor if you are constipated or if you are feeling any discomfort or tenderness around your anus when you are trying to move your bowels. People may have a flare up of haemorrhoids after chemotherapy. You may need a gentle laxative to help soften your bowel motion.

### **Hair loss**

For most of us, the thought of losing our hair is very frightening. Hair loss is unfortunately a very common side-effect of chemotherapy and some forms of radiotherapy. It is, however, usually only temporary. The hair starts to fall out within a couple of weeks of treatment and tends to grow back three to six months later. In the meantime there are lots of things that you can do to make yourself feel more comfortable.

Avoiding the use of heat or chemicals and only using a soft hair-brush and a mild baby shampoo can help reduce the itchiness and scalp tenderness which can occur while you are losing your hair. When drying your hair, pat it gently rather than rubbing it with a towel. Some people find it more comfortable to simply have a short hair cut when they notice that their hair is starting to fall out.



You need to avoid direct sunlight on your exposed head (by wearing a hat or similar head covering), because chemotherapy (and radiotherapy) makes your skin even more vulnerable to the damaging effects of the sun (i.e. sunburn and skin cancers). Remember that without your hair, your head can get quite cold, so a beanie might be useful, especially if you are in an air-conditioned environment like a hospital. Hair can also be lost from your face and body.

*Look Good ... Feel Better* is a free community service that runs programs on how to manage the appearance-related side-effects of cancer treatments. The volunteer beauty therapists who run these programs give useful advice and demonstrations on how to manage hair loss including the use of hats, wigs, scarves or turbans. You might like to visit their website at [www.lgfb.org.au](http://www.lgfb.org.au) or free call them on 1800 650 960.

### ***Fatigue***

Most people experience some degree of tiredness in the days and weeks following treatment. Having plenty of rest and light exercise each day may help to make you feel better during this time. Getting out into the fresh air and doing some gentle exercise is important for your general feeling of wellbeing and it also may help to reduce your fatigue. It is also important to listen to your body and rest when you are tired.

### **Fertility**

Some types of chemotherapy and radiotherapy may cause a temporary or permanent reduction in your fertility. It is very important that you discuss any questions or concerns you might have regarding your future fertility with your doctor. It is best to have this discussion with your doctor *before* you commence your treatment.

In women, some types of chemotherapy and radiotherapy can cause varying degrees of damage to the normal functioning of their ovaries. In some cases this leads to menopause (change of life) earlier than expected. In men, sperm production can be impaired for a while but the production of new sperm may become normal again in the future.

There are some options for preserving your fertility, if necessary, while you are having treatment for Hodgkin lymphoma. These are described below.

### ***Protecting your fertility - Men***

Sperm banking is a relatively simple procedure whereby the male donates semen, which is then stored at a very low temperature (cryopreserved), with the intention of using it to achieve a pregnancy in the future. You should discuss sperm banking with your doctor before starting any treatment that might impact on your fertility. In some cases the individual may not be a suitable candidate for sperm banking when they are first diagnosed because they are too ill and therefore unable to produce the sperm in sufficient quantity or quality.

If possible, semen should be donated on more than one occasion. It is important to realise that there are many factors that can affect the quality and quantity of sperm collected in a semen donation, and its viability after it is thawed out. There is no guarantee that you and your partner (or future partner) will be able to achieve a pregnancy and healthy baby in the future. You should raise any concerns you have with your doctor who can best advise you on your fertility options.

### ***Protecting your fertility - Women***

There are several approaches that may be used to protect a woman's fertility. These are outlined below.

*Embryo storage* - this involves collecting your eggs, usually after having drugs to stimulate your ovaries to produce a number of eggs, so that more than one egg can be collected. This process takes some time. Once they are collected they are then fertilised with your partner's sperm and stored to be used at a later date.

*Egg Storage*: your unfertilised eggs can also be collected and stored in a similar manner.

*Ovarian tissue storage* - this involves the removal and storage, at a very low temperature, of some ovarian tissue (cryopreservation). It is hoped that, at a later date, the eggs contained in this tissue can be matured, fertilised and used to achieve a pregnancy in the future.

It is important to reiterate that the methods that are described here for women are still relatively new. and for many reasons achieving a

pregnancy and subsequently a baby is *not* guaranteed by using any of them. However, it is hoped that future research will improve your chances of having a baby. In addition, some are time consuming and costly while others may simply not be acceptable to you or your partner.

### ***Menopause***

The onset of menopause in these circumstances can be sudden and understandably, very distressing.

It is important to discuss the possibility of an early menopause with your doctors **before** your treatment has begun. Medications may be prescribed that may help prevent an early menopause and reduce your symptoms.

Hormone changes can lead to many of the classic symptoms of menopause including menstrual changes, hot flushes, sweating, dry skin, vaginal dryness and itchiness, headache and other aches and pains. Some women experience decreased sexual drive, anxiety and even depressive symptoms during this time. It is important that you discuss any changes to your periods with your doctor or nurse. He or she may be able to advise you, or refer you on to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps you can take to reduce your symptoms.



## Radiotherapy

Radiotherapy uses high energy x-rays to kill cancer cells and shrink tumours. Radiotherapy is regarded as *local therapy* because it only destroys cancer cells in the treated area.

The *radiation field* is the area of the body which is being treated. Common radiation fields include the *mantle* field (treating the lymph nodes of the neck, chest and armpit), the upper abdominal field (treating the lymph nodes in the abdomen and sometimes the spleen) and the pelvic field (treating lymph nodes in the hips and groin).

### ***What is involved in radiotherapy?***

Before you start treatment, the Radiation Oncologist (doctor who specialises in treating people with radiotherapy) will carefully calculate the correct dose of radiation therapy for you. The areas of your body that need to be treated will be marked with tiny ink dots on your skin using a special pen.

Radiotherapy is usually given in small doses (also known as fractions) each week day (Monday to Friday) over a few weeks. It is given in the Radiation Oncology department of the hospital and while you do not need to be admitted to hospital as an inpatient for this treatment, you may need to organise some accommodation for this time, if you live a long way from the hospital. The social worker or nurses can assist you with this.

When you are having radiotherapy you usually lie on a table underneath the radiotherapy machine which delivers the planned dose of radiation. Important structures such as your heart and lungs are shielded as much as possible to ensure that they are not affected by the treatment given. Radiotherapy is painless, in fact you do not see or feel anything during the actual treatment. You will however, need to stay perfectly still for a few minutes while the treatment is taking place. You might like to take along some music to help you relax.

### ***Side-effects of radiotherapy***

Radiotherapy can cause similar side-effects to those caused by chemotherapy including nausea and vomiting, increased sun sensitivity (especially on the site radiated) hair loss and fatigue.

In general however, the side-effects experienced with radiotherapy depend on the area of the body which has been treated. For example, radiotherapy to the abdomen is more likely to cause nausea and vomiting, while hair loss is usually confined to the areas of the body being treated.

### ***Skin reactions***

Radiotherapy can cause a reddening of the skin which may also flake and become itchy. **The nursing staff at the radiotherapy department will advise you on how to care for your skin while you are having treatment.** Gentle washing (avoiding perfumed products like scented soaps) and drying (patting rather than rubbing) is often recommended. You should also avoid any creams or moisturisers that contain traces of metals. Check with the radiotherapy staff if you are unsure. Also, you should avoid direct sunlight on any area of skin that has received radiotherapy, even after the therapy has finished.

### ***Parotitis***

Parotitis is an inflammation of the saliva-producing glands in the mouth which can occur if these glands are within the treatment field used. Parotitis causes dryness of the mouth and jaw pain which usually settles down within a few days once the inflammation subsides.

## **Stem Cell Transplantation**

For some people, very high doses of chemotherapy or radiotherapy are needed to effectively treat their lymphoma. As a side effect of these treatments, normal bone marrow and bone marrow stem cells are also destroyed and need to be replaced using an *autologous* stem cell transplant\* (also known as an autologous *peripheral blood stem cell* or *bone marrow transplant*). This type of treatment involves collecting stem cells, usually from your blood stream, storing them and then giving them back to you after you have received high doses of chemotherapy. It is generally only offered to patients who have relapsed or are at high risk of relapse, and to those for whom standard (conventional) treatment has not worked.

In a very small number of cases an allogeneic stem cell transplant\* using a suitably matched stem cell donor may be considered. Because of the risks associated with this form of treatment for Hodgkin lymphoma, it is generally only used in younger patients.

A stem cell transplant is only offered if your doctor feels that it will be of benefit to you.

## **Steroid therapy**

Steroids are hormones which are produced naturally by the body. They can also be made in the laboratory and they play an important role in the management of lymphoma. *Prednisone* and *Dexamethasone* are examples of steroids that are often given as part of a chemotherapy regime. Steroids work in this instance, by directly killing lymphoma cells, and reducing side effects such as nausea.

## **Side-effects of steroid therapy**

The types of side-effects seen with steroids depend largely on how long they are used for, and the dose given. If you are using steroids for a short time you may notice that your appetite increases or you may feel more restless than usual. Some people find it more difficult to get to sleep at night and sleeping tablets or other natural therapies are sometimes recommended.

Some people may experience mood changes or depression. If you have a history of mental health concerns, particularly depression, please inform your doctor before commencing steroid therapy.

Many of the side-effects of steroids are temporary and should pass once you finish taking them.

Long-term use may cause some other effects such as fluid retention, problems with blood sugar levels and an increased susceptibility to infections. Aching joints such as the knees and hips have also been reported. Remember to tell your doctor and nurses about any side-effects you are having as they can usually suggest ways to help you.

*\*There are separate Leukaemia Foundation booklets called 'Understanding Autologous Transplants - a guide for patients and families' and 'Understanding Allogeneic Transplants - a guide for patients and families', which provide more details on these types of treatments.*

## Clinical trials

Clinical trials (also called research studies) test new treatments, or administer standard treatments in a new way, and compare their outcomes to established treatments both to see if the new treatment regimen works better, and to compare the side effects. Some clinical trials are randomised, so that some patients will be receiving the new experimental treatment and others receive the current standard treatment. Clinical trials are important because they provide vital information about how treatment can be improved. Clinical trials sometimes give access to new therapies that have been tested elsewhere but are not yet available locally.

If you are considering taking part in a clinical trial make sure that you understand the reasons for the trial and what it involves for you. You also need to understand the benefits and risks of the trial before you can give your consent. Talk to your doctor who can guide you in making the best decision for you.\*

## Informed consent

Giving an **informed** consent means that the potential risks and potential benefits of a proposed procedure or treatment have been fully explained to you. You will then be asked if you are willing to comply with the requirements of the trial, including treatments, tests and the collection of relevant information about you and your disease. If you feel happy that you have adequate information to make such a decision, you may then give your informed consent.

You should never feel compelled to be in a clinical trial. The decision to participate must always be voluntary, after you have received all the necessary information. Even after you have agreed to be in a clinical trial and signed the consent form, you can change your mind, whether or not trial treatment has already started.

\* You can also refer to the information sheets about clinical trials on our website. There are also questions that you can ask your doctor. See <http://www.leukaemia.org.au/web/research/clinicaltrials.php>

***“How can I help with blood cancer research?”***

The Australasian Leukaemia and Lymphoma Group (a clinical trials research group) has established a national Leukaemia and Lymphoma Tissue Bank at the Princess Alexandra Hospital in Brisbane, Queensland. The Tissue Bank is a temperature controlled facility for storing clinical tissue samples to be used in approved research into leukaemia, lymphoma, myeloma and related blood disorders. Current research focuses on understanding the development of cancers, why different patients respond differently to current treatments and therapies that may be more effective (especially those being assessed in clinical trials). The clinical tissue samples used for this research come from blood, bone marrow and other tissue biopsy samples from patients' routine testing and from samples taken for monitoring during clinical trials.

In order to donate your blood and/or bone marrow samples to the Tissue Bank you will need to sign a consent form at the time of your diagnosis. This can be obtained from your clinician. Be assured, donating does not involve any additional procedures, it simply involves saving and storing in the Tissue Bank any excess blood or bone marrow extracted during your routine tests. Samples are also welcomed from relapsed patients at re-diagnosis.

The donation of your tissue sample is an invaluable way to support blood cancer research and could bring us closer to finding a cure. Tissues from blood cancer patients are precious materials for researchers because these cancers are relatively rare and are vital for finding cures. For further information on the Leukaemia and Lymphoma Tissue Bank go to:

<http://www.leukaemia.org.au/web/research/tissuebank.php>

## Complementary therapies

Complementary therapies are therapies which are not considered standard medical therapies. Many people however, find that they are helpful in coping with their treatment and recovery from disease. There are many different types of complementary therapies including yoga, exercise, meditation, prayer, acupuncture, relaxation and herbal and vitamin supplements.

Complementary therapies should 'complement' or assist with the recommended medical treatment for Hodgkin lymphoma. **They should not be used instead of, or as an alternative to medical treatment.** It is important to realise that no complementary or alternative treatment alone has proven to be effective against Hodgkin lymphoma. It is also important to let your doctor or nurse know if you are using any complementary or alternative therapies, in case they interfere with the effectiveness of chemotherapy or other treatments you may be having.

### Nutrition\*

A healthy and nutritious diet is important in helping your body to cope with your disease and treatment. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any radical changes to the way you eat. You may wish to see a nutritionist or dietician who can advise you on planning a balanced and nutritious diet.



If you are thinking about using herbs or vitamins it is very important to talk this over with your doctor first. Some of these substances can interfere with the effectiveness of chemotherapy or other treatment you are having.

*\*There is a separate Leukaemia Foundation booklet called 'Eating well - A practical guide for people living with leukaemias, lymphomas, myeloma and related blood disorders', which provides more detail.*

## BODY IMAGE, SEXUALITY AND SEXUAL ACTIVITY

It is likely that the diagnosis and treatment of Hodgkin lymphoma will have some impact on how you feel about yourself as a man or a woman and as a 'sexual being'. Hair loss, skin changes and fatigue can all interfere with feeling attractive.

As mentioned previously, *Look Good ... Feel Better* is a free community service that runs programs on how to manage the appearance-related side-effects of cancer treatments. You might like to visit their website at [www.lgfb.org.au](http://www.lgfb.org.au) or free call them on 1800 650 960.

During treatment, you may sometimes experience a decrease in libido (your body's sexual urge or desire), without there being any obvious reason. It may take some time for things to return to 'normal'. If sexual intercourse is uncomfortable, remember that there are other pleasurable sexual activities which don't involve penetration. Gentle touching or just cuddling your partner may be satisfying enough. It is however, perfectly reasonable and safe to have sex while you are on treatment or shortly afterwards, but there are some precautions you need to take.

It is usually recommended that you or your partner do not become pregnant during and soon after the treatment period, as some of the treatments given might harm the developing baby. As such you need to ensure that you or your partner use a suitable form of contraception. Partners are sometimes afraid that sex might in some way harm the patient. This is not likely as long as the partner is free from any infections and the sex is relatively gentle. Finally, if you are experiencing vaginal dryness, a lubricant can be helpful. This will help prevent irritation.

If you or your partner have any questions or concerns regarding sexual activity and contraception don't hesitate to discuss these with your doctor or nurse or ask for a referral to a doctor or health professional who specialises in sexual issues. There may even be a particular person in your treating team with whom you trust and feel comfortable discussing such personal issues.

## POTENTIAL LATE EFFECTS OF TREATMENT

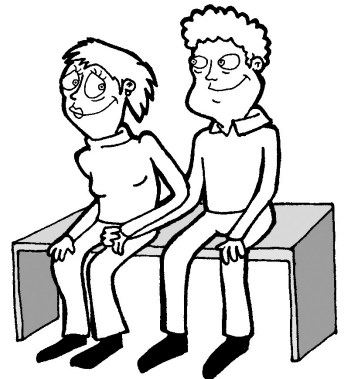


Many people enjoy long and healthy lives after being successfully treated for Hodgkin lymphoma. Sometimes however, the treatment can affect a person's health for months or even years after it has finished. These are called 'late effects'. For example, radiotherapy to the neck may affect the function of the thyroid gland, causing *hypothyroidism* (reduced thyroid function). Regular blood tests

will monitor for this, and if the function of the thyroid is found to be abnormal, steps can be taken to correct it.

Radiotherapy to the chest and some chemotherapy drugs occasionally causes heart and lung problems, sometimes years later. Regular tests can be done to monitor the function of these organs.

People who have been treated with chemotherapy and radiation therapy may be at a higher risk of developing other diseases such as *myelodysplasia* (bone marrow disease) and other (secondary) cancers including leukaemia, and *melanoma* (a type of skin cancer). Evidence also suggests that radiotherapy to the chest at a younger age may increase the chances of developing lung cancer or breast cancer later in life. It is therefore important that people who have had these treatments minimise their risk of developing secondary cancers by avoiding ultraviolet radiation from the sun, by not smoking and by having regular screening for breast cancer. After your treatment has finished, drawing up a late effects plan with your doctor or nurse can help you to manage your late effects, and will let you know what you will need to have regularly monitored in the future, and when.



## MAKING TREATMENT DECISIONS

Many people feel overwhelmed when they are diagnosed with Hodgkin lymphoma. In addition to this, waiting for test results and then having to make decisions about proceeding with the recommended treatment can be very stressful. Some people do not feel that they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given, or that they are being rushed into making a decision. It is important that you feel you have enough information about your illness and all of the treatment options available, so that you can make *your own* decisions about which treatment to have.

Before going to see your doctor, make a list of the questions you want to ask. It is a good idea to keep a notebook or some paper and a pen handy, as many questions come to mind in the early hours of the morning.

Sometimes it is hard to remember everything the doctor has said. It may help to take bring a family member or a friend along to your appointments with you, so they can write down the answers to your questions or prompt you to ask any questions you may have forgotten to ask. This person can be an extra set of ears, or simply be there to support you.

Your treating doctor (haematologist) will spend time discussing with you and your family what he or she feels is the best option for you. Feel free to ask as many questions as you need to, at any stage. You are involved in making important decisions regarding your wellbeing and you should feel that you have enough information to do this, and that the decisions made are in your best interests. Remember, you can always request a second opinion if you feel this will make you more comfortable about the decisions being made.

## INFORMATION AND SUPPORT\*

People cope with a diagnosis of Hodgkin lymphoma in different ways, and there is no right or wrong or standard reaction. For some people, the diagnosis can trigger any number of emotional responses ranging from denial to devastation. It is not uncommon to feel angry, helpless and confused. Naturally people fear for their own lives or that of a loved one.

It is worth remembering that information can often help to take away the fear of the unknown. It is best for patients and families to speak directly to their doctor regarding any questions they might have about their disease or treatment. It can also be helpful to talk to other health professionals including social workers, psychologists or nurses who have been specially educated to take care of people with haematological diseases. Some people find it useful to talk with other patients and family members who understand the complexity of feelings and the kinds of issues that are experienced by people living with an illness of this nature.

**If you have a psychological or psychiatric condition, please inform your doctor and don't hesitate to request additional support from a mental health professional.**

Many people are concerned about the social and financial impact of the diagnosis and treatment on their families. Normal family routines are often disrupted and other members of the family may suddenly have to fulfil roles they are not familiar with, for example, cooking, cleaning, doing the banking and taking care of children.

There are a variety of programs designed to help ease the emotional and financial strain associated with cancer and its treatment. The Leukaemia Foundation is there to provide you and your family with information and support to help you cope during this time. Contact details for your state office of the Leukaemia Foundation are provided on the back of this booklet.

*\*There is a separate Leukaemia Foundation booklet called 'Living with Leukaemias, Lymphomas, Myeloma and Related Disorders'. This booklet addresses the impact of the diagnosis, family matters, support, survivorship, and other general issues around treatment.*

## USEFUL INTERNET ADDRESSES

- Leukaemia Foundation  
[www.leukaemia.org.au](http://www.leukaemia.org.au)
- American Cancer Society  
[www.cancer.org](http://www.cancer.org)
- Australian Bone Marrow Donor Registry  
[www.abmdr.org.au](http://www.abmdr.org.au)
- Australian Cancer Trials Registry  
[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)
- Cancer Council of Australia  
[www.cancer.org.au](http://www.cancer.org.au)
- CanTeen – The Australian Organisation for Young People living with Cancer  
[www.canteen.org.au](http://www.canteen.org.au)
- International Lymphoma Coalition  
[www.lymphomacoalition.org](http://www.lymphomacoalition.org)
- Leukaemia Foundation's Online Discussion Forum  
[www.talkbloodcancer.com](http://www.talkbloodcancer.com)
- Leukemia & Lymphoma Society of America  
[www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org)
- Leukaemia Research Fund (UK)  
[www.leukaemia-research.org.uk](http://www.leukaemia-research.org.uk)
- Look Good ... Feel Better program  
[www.lgfb.org.au](http://www.lgfb.org.au)
- National Cancer Institute (USA)  
[www.cancer.gov/cancerinfo](http://www.cancer.gov/cancerinfo)
- Redkite – Practical support for young people with cancer  
[www.redkite.org.au](http://www.redkite.org.au)

# GLOSSARY

**Alopecia**

Hair loss. This is a side effect of some kinds of chemotherapy and radiotherapy. It is usually temporary.

**Anaemia**

A reduction in haemoglobin in the blood. Haemoglobin normally carries oxygen to all the body's tissues. Anaemia causes tiredness, paleness and sometimes shortness of breath.

**Antibodies**

Naturally produced substances in the blood, made by white blood cells called B-lymphocytes or B-cells. Antibodies target antigens on other substances such as bacteria, viruses and some cancer cells and cause their destruction.

**Antiemetic**

A drug which prevents or reduces feelings of sickness.

**Antigen**

A substance, usually on the surface of a foreign body such as a virus or bacteria that stimulates the cells of the body's immune system to react against it by producing antibodies. 'Antigen' is also the general term used to describe proteins found on the surface of all body cells. Here, antigens act like flags identifying different types of cells.

**B-lymphocyte (B-cell)**

A type of white cell normally involved in the production of antibodies to combat infection.

**Bone marrow**

The tissue found at the centre of many flat or big bones of the body. The bone marrow contains stem cells from which all blood cells are made.

**Blood count**

A routine blood test that measures the number and type cells circulating in the blood.

**Cancer**

A malignant disease characterised by uncontrolled growth, division, accumulation, and invasion into other tissues of abnormal cells from the original site where the cancer started. Cancer cells can grow and multiply to the extent that they eventually form a lump or swelling. This is a mass of cancer cells known as a tumour. Not all tumours are due to cancer; in which case they are referred to as non-malignant or benign tumours.

**Cannula**

A short, thin, flexible, plastic tube which can be inserted into a vein to allow administration of drugs and fluids directly into the blood stream.

**Central venous catheter (CVC)**

Also known as a central venous access device (CVAD). Commonly referred to as a central line, is a long, thin, flexible, plastic tube passed through the large veins of the neck, chest or groin and into the central blood circulation. It can be used for taking samples of blood, giving intravenous fluids, blood, chemotherapy and other drugs without the need for repeated needles.

**Chemotherapy**

Single drugs or combinations of drugs, which may be used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and this is responsible for some common side-effects, including hair loss and a sore mouth. Most side-effects are temporary and reversible.

**Complete remission**

Anti-cancer treatment has been successful and so much of the disease has been destroyed that it can no longer be detected using current technology.

**Computerised axial tomography (CT scan or CAT scan)**

A specialised x-ray or imaging technique that produces a series of detailed cross-sectional images, that can be used to reconstruct three dimensional (3D) images of the internal structures of the body.

**Cure**

This means that there is no evidence of disease and no sign of it reappearing, even many years later (usually after five years).

**Diaphragm**

A layer of muscle under the ribs, that separates the stomach from the chest and used for breathing.

**Disease progression**

Where the disease is getting worse on or off treatment.

**Echocardiogram**

A special ultrasound scan of the heart.

**Electrocardiogram (ECG)**

Recording of the electrical activity of the heart.

**Gallium scan**

A specialised x-ray or imaging technique using radioactive gallium (a type of liquid metal) which is injected into the blood stream and collects in some tumours.

**Growth factors**

A complex family of proteins produced by the body to control the growth, division and maturation of blood cells by the bone marrow. Some are now available as drugs as a result of genetic engineering and may be used to stimulate normal blood cell production following chemotherapy or bone marrow or peripheral blood cell transplantation. For example G-CSF (granulocyte colony stimulating factor).

**Haematologist**

A doctor who specialises in the diagnosis and treatment of diseases of the blood, bone marrow and immune system.

**Haemopoiesis or haematopoiesis**

The formation of blood cells.

**Hickman catheter**

A type of central venous catheter (see above) used for patients undergoing intensive treatment such as bone marrow or peripheral

blood cell transplantation. It may have a single, double or triple tube (or lumen).

**High-dose therapy**

The use of higher than normal doses of chemotherapy to kill off resistant and/or residual (left over) cancer cells that have survived standard-dose therapy.

**High-grade lymphomas**

Fast-growing lymphomas.

**Hodgkin lymphoma**

A type of lymphoma - cancer of the lymphatic system. It is characterised by the presence of Reed-Sternberg cells. All other types of lymphoma come under the heading of non-Hodgkin lymphomas or B and T-cell lymphomas.

**Hypothyroidism**

A reduction in the normal function of the thyroid gland.

**Immune system**

The body's defense system against infection and disease.

**Immunocompromised**

When someone has reduced immune function.

**Immune suppression**

The use of drugs to reduce the function of the immune system.

**Leukaemia**

A cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal and/or immature blood cells. These cells take over the bone marrow often causing a fall in blood counts. If they spill out into the bloodstream however, they can cause very high abnormal white cell counts.

**Localised disease**

Disease that is confined to a small area or areas in the body.

**Low-grade lymphoma**

Slow-growing lymphomas.

**Lymph nodes or glands**

Structures found throughout the body, for example in the neck (cervical), groin (inguinal), armpit (axilla) and abdomen, which contain both mature and immature lymphocytes. There are millions of very small lymph glands in all organs of the body.

**Lymphatic system**

A vast network of lymphnodes, connected by ducts, similar to blood vessels, that branch out into all the tissues of the body. These ducts carry lymph, a colourless watery fluid that transport lymphocytes, specialised white cells that protect us against disease and infection. The lymphatic system is part of the body's immune system.

**Lymphocytes**

Specialised white cells, which are involved in defending the body against disease and infection. There are two types of lymphocytes: B-lymphocytes and T-lymphocytes. They are also called B-cells and T-cells.

**Lymphoma**

Cancer that arises in a lymph node or the lymphatic system.

**Magnetic resonance imaging (MRI)**

A body scanning technique which uses a very strong magnet and radio waves to produce very clear and detailed three dimensional (3D) images of internal organs and structures.

**Malignancy**

A term applied to tumours characterised by uncontrolled growth and division of cells and spread to other parts of the body (see cancer).

**Mucositis**

Inflammation of the lining of the mouth and throat, which also can extend to the lining of the whole of the gastrointestinal tract (stomach and intestines).

**Neutropenia**

A reduction in the number of circulating neutrophils, an important type of white cell to fight bacterial infections. Neutropenia is associated with an increased risk of infection.

**Neutrophils**

Neutrophils are the most common type of white cell. They are needed to mount an effective fight against infection, especially bacteria and fungi.

**Non-Hodgkin lymphomas**

Also known as B and T-cell lymphomas. The name historically used to describe a group of lymphomas (cancers of the lymphatic system) that differ in important ways from Hodgkin lymphomas. Non-Hodgkin lymphomas can be slow growing (low grade), or fast growing (intermediate or high-grade) and may be treated in a variety of ways.

**Oncologist**

General term used for a specialist doctor who treats cancer by different means, e.g. medical, radiation, surgical oncologist.

**Partial remission**

The tumour shrinks to less than half its original size following treatment.

**Pathologist**

A doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.

**PICC line**

Peripherally inserted central venous catheter (see central venous catheter) inserted in the middle of the forearm. PICCs are sometimes used for people having chemotherapy.

**Positron emission tomography (PET)**

A special type of x-ray or imaging technique capable of distinguishing between normal tissue and areas of cancer deep in the body. It uses a radioactive tracer molecule (usually glucose), which is taken up by highly metabolically active cells, such as the brain, heart and aggressive cancers.

**Prognosis**

An estimate of the likely course of a disease.

**Radiotherapy (radiation therapy)**

The use of high energy x-rays to kill cancer cells and shrink tumours.

**Radiation field**

The area of the body being treated with radiotherapy.

**Relapse**

The return of the original disease.

**Resistant or refractory disease**

The disease is not responding to treatment.

**Remission**

This can be partial or complete and means that a significant reduction in the amount of disease has resulted from successful treatment. This is not the same as a cure as relapse may still occur.

**Spleen**

An organ that accumulates lymphocytes and functions as part of the immune system and destroys blood cells at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side, under the ribs. It cannot normally be felt on examination unless it is enlarged. It is often enlarged in diseases of the blood – this is known as *hypersplenism*.

**Splenomegaly**

Another term used to describe an enlarged spleen.

**Stable disease**

When the disease is stable it is not getting significantly better or worse with treatment.

**Stage**

The extent or spread of disease in the body.

**Staging**

An assessment of the extent or spread of disease in the body.

**Standard therapy**

The most effective and safest therapy currently being used.

**Stem cells**

Stem cells are the primitive cells that can create more than one cell type. There are many different types of stem cells in the body. Bone marrow (blood) stem cells have the ability to grow and produce all the different blood cells including red cells, white cells and platelets.

**Stem cell transplant (peripheral blood stem cell or bone marrow transplant)**

These treatments are used to support the use of high-dose chemotherapy and / or radiotherapy in the treatment of a wide range of blood cancers including leukaemias, lymphomas, myeloma, certain solid tumours, and other serious diseases.

**T-lymphocyte (T-cell)**

A type of white cell involved in controlling immune reactions.

**Thymus**

A gland found behind the breast bone (sternum) involved in the maturation of T-lymphocytes (T-cells).

**Tumour**

An abnormal mass of cells which may be non-malignant (benign) or malignant (cancerous).

**Ultrasound**

Pictures of the body's internal organs built up from the interpretation of reflected sound waves.

**White cells**

Specialised blood cells of the immune system that protect the body against infection. There are five main types of white cells: neutrophils, eosinophils, basophils, monocytes and lymphocytes.

**X-ray**

A form of ionising radiation used in diagnosis and treatment.



**Please send me a copy of the following information booklets:**

- Eating Well: A practical guide for people living with leukaemias, lymphomas and myeloma
- Living with Leukaemias, Lymphomas, Myeloma & Related Blood Disorders: Information & Support
- Understanding Leukaemias, Lymphomas, Myeloma and Related Blood Disorders
- Understanding Acute Lymphoblastic Leukaemia in Adults
- Understanding Acute Lymphoblastic Leukaemia in Children
- Understanding Acute Myeloid Leukaemia
- Understanding Allogeneic Transplants
- Understanding Amyloidosis
- Understanding Autologous Transplants
- Understanding Chronic Lymphocytic Leukaemia
- Understanding Chronic Myeloid Leukaemia
- Understanding Hodgkin Lymphoma
- Understanding Non-Hodgkin Lymphomas
- Understanding Myelodysplastic Syndromes
- Understanding Myeloma
- Understanding Myeloproliferative Disorders
- Young Adults with a Blood Cancer

**Or information about:**

- Receiving the Foundation's Lymphoma newsletter
- The Leukaemia Foundation's Support Services
- Workplace giving
- Regular deduction scheme
- National fundraising campaigns
- Volunteering
- Receiving the Foundation's newsletters

Name: .....

Street or Postal Address: .....

Suburb.....

State/Postcode .....

Email: ..... Tel: (.....)

Please send to:

Leukaemia Foundation, GPO Box 9954, In Your Capital City  
or Freecall 1800 620 420

or email: [info@leukaemia.org.au](mailto:info@leukaemia.org.au)

Further information is available on the Leukaemia Foundation's website  
[www.leukaemia.org.au](http://www.leukaemia.org.au)









# Leukaemia Foundation

®  
VISION TO CURE  
MISSION TO CARE

This information booklet is produced  
by the Leukaemia Foundation and is one in a series on blood  
cancers and related disorders.

Some booklets are also available in other languages. Copies of this  
booklet and the other booklets can be obtained from the  
Leukaemia Foundation in your state by contacting us on

Freecall: 1800 620 420  
Email: [info@leukaemia.org.au](mailto:info@leukaemia.org.au)  
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October 2011