NON-HODGKIN LYMPHOMA

A guide for patients and families
CONTENTS

Acknowledgements 4
Introduction 5
The Leukaemia Foundation 6
Lymphoma 10
Bone marrow, stem cells and blood 11
The Lymphatic System 16
What is lymphoma? 18
What causes lymphoma? 19
What are the signs and symptoms of lymphoma? 20
Which doctor? 21
How is lymphoma diagnosed? 21
Types of non-Hodgkin lymphoma 23
Treatment 33
Body image, sexuality and sexual activity 53
Potential late effects of treatment 54
Making treatment decisions 55
Glossary of terms 59
Making a donation 67
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The Leukaemia Foundation values feedback from people affected by a lymphoma and the healthcare professionals working with them. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact us at info@leukaemia.org.au.

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INTRODUCTION

This booklet has been written to help you, your family, friends and loved ones understand more about lymphomas.

Some of you may be feeling anxious or a little overwhelmed if you, or someone you care for, has been diagnosed with lymphoma. This is normal. Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family, friends and loved ones. Whatever point you are at, we hope 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. Some of you may require more information than is contained in this booklet so 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.

We hope you find this booklet useful in providing support and information. We would appreciate any feedback from you so we can continue to help you and your family in the future.
The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life.

It exists only because of the generous and ongoing support of the Australian community.

Each year, the Leukaemia Foundation helps more than 750 families from regional and rural Australia by providing free accommodation in our capital cities so they can access life-saving treatment at major hospitals.

Our transport service helps thousands get to and from medical appointments, driving more than one million kilometres each year to ensure people get the medicines they need to beat their blood cancer.

The Leukaemia Foundation also provides counselling, comprehensive information, education and support programs and financial assistance to help the 60,000 Australians who are currently living with a blood cancer.

The Leukaemia Foundation also funds researchers who are working tirelessly to discover safer and more effective treatments that will save lives and help people lead a better quality of life.

Supporters ensure the Leukaemia Foundation can continue to give those impacted by blood cancer a strong voice, advocating for change and ensuring all Australians who need them have easy access to the very best blood cancer treatments.
Support Services

The Leukaemia Foundation has a team of highly trained and caring support staff with qualifications and experience in nursing or allied health who work across the country.

We can offer individual support and care to you and your family when you need it.

Support Services may include:

Information

The Leukaemia Foundation has a range of booklets, DVDs, fact sheets 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 leukaemia.org.au.

Education & Support programs

The Leukaemia Foundation offers you and your family both lymphoma-specific and 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 wellbeing.

Emotional support

A diagnosis of 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 staff can provide you and your family with much needed support during this time.

Blood Buddies

This is a program for people newly diagnosed with lymphoma to be introduced to a trained ‘Buddy’ who has been living with lymphoma for at least two years, to share their experience, their learning, and to provide support.
**Telephone discussion forums**

This service enables anyone throughout Australia who has or has been affected by lymphoma to share their experiences, provide tips, and receive education and support in a relaxed forum. Each discussion is facilitated by a member of the Leukaemia Foundation support team who is a trained health professional.

**Accommodation**

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

**Transport**

The Leukaemia Foundation also assists with transporting people 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 everyday life for you and your family and there may be practical things the Leukaemia 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.

Advocacy
The Leukaemia Foundation is a source of support for you as you navigate the health system. While we do not provide treatment recommendations, we can support you while you weigh up your options. We may also provide information on other options such as special drug access programs, and available clinical trials.

Contacting us
The Leukaemia Foundation provides free services and support across Australia. Every person’s experience of living with lymphoma is different. It’s not always easy, but you don’t have to do it alone.

Please call 1800 620 420 to speak to a support staff member or to find out more about the services the Leukaemia Foundation offers.

Alternatively, contact us via email on info@leukaemia.org.au or visit leukaemia.org.au.

I took time off work to focus on my health and wellness. It was the best thing I could have done.
Lymphoma is the most common type of a group of cancers called blood cancers. Blood cancers occur in cells that originate in the bone marrow, and are defined by the uncontrolled growth of faulty cells. In lymphoma, the majority of these cancerous cells are found in the lymphatic system, but can also be found in other areas of the body.

To understand lymphoma and its impacts on our body we first need to understand the cells involved, and where they are formed. For this, we need to understand the bone marrow and the cells that are formed there, blood cells.
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 haematopoiesis. There are three main types of blood cells: red cells, white cells and platelets.

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

You might like to think of the bone marrow as the blood cell factory. The main workers at the factory are the 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 because they have limited life spans.

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

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

Lymphoid (‘lim-foid’) stem cells develop into other types of white cells including T-cells, B-cells and Natural Killer Cells.
Growth factors and cytokines
All normal blood cells have a limited lifespan in the circulation and need to be replaced on a continual basis. This means that the bone marrow remains very active throughout life. Natural chemicals circulating in your blood called growth factors, or cytokines, control this process of blood cell formation. Each of the different blood cells is produced from stem cells under the guidance of a different growth factor.

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

Blood
Blood consists of blood cells and plasma. Plasma is a straw-coloured fluid that blood cells use to travel around your body and also contains many important proteins and chemicals.
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 uses this oxygen to create energy.

**Haematocrit**
About 99% of all blood cells in circulation are red blood cells. The percentage 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.

**Anaemia**
Anaemia is 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 may feel rundown 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 may be given to restore the red blood cell numbers and therefore the haemoglobin to more normal levels.

**Normal ranges for adults:**

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Haemoglobin (Hb)</strong></td>
<td>130 - 170 g/L</td>
<td>120 - 160 g/L</td>
</tr>
<tr>
<td><strong>Haematocrit (Hct)</strong></td>
<td>40 - 52%</td>
<td>36 - 46%</td>
</tr>
<tr>
<td><strong>White cell count (WBC)</strong></td>
<td>3.7 - 11.0 x 10⁹/L</td>
<td></td>
</tr>
<tr>
<td><strong>Neutrophils (neut)</strong></td>
<td>2.0 - 7.5 x 10⁹/L</td>
<td></td>
</tr>
<tr>
<td><strong>Platelets (Plt)</strong></td>
<td>150 - 400 x 10⁹/L</td>
<td></td>
</tr>
</tbody>
</table>
White cells
White cells, also known as leukocytes, fight infection. The following is a list of some of the different types of white cells:

**Neutrophils:** mainly kill bacteria and remove damaged tissue. Neutrophils are often called the first line of defence when infections occur. They are often the first white blood cell at the site of infection and attempt to destroy the foreign pathogen before it becomes a problem to the body.

**Eosinophils:** mainly kill parasites.

**Basophils:** mainly work with neutrophils to fight infection.

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

**B-cells:** mainly make antibodies which target micro-organisms, particularly bacteria.

**T-cells:** mainly kill viruses, parasites and cancer cells, and produce cytokines which can recruit other cells to make antibodies which target micro-organisms.

These white cells work together to fight infection as well as having unique individual roles in the fight against infection.

Neutropenia
Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1 (1 x 10^9/L), you are at an increased risk of developing more frequent and sometimes severe infections.

Platelets
Platelets are 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 (for example by a cut) the platelets gather at the site of the injury, stick together and form a plug to help stop the bleeding. They also release chemicals, called clotting factors that are required for the formation of blood clots.

Thrombocytopenia
Thrombocytopenia is the term used to describe a reduction in the platelet count to below normal. If your platelet count drops too low, you are at an increased risk of bleeding and tend to bruise easily. Each treatment centre will have their own guidelines on the specific platelet count level when interventions may need to be taken. Platelet transfusions are sometimes given to return the platelet count to a safer level.
Children

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

If your child is being treated for 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.

<table>
<thead>
<tr>
<th></th>
<th>1 month</th>
<th>1 year</th>
<th>3 years</th>
<th>5 years</th>
<th>9 years</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Haemoglobin g/L</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>102-130</td>
<td>104-132</td>
<td>107-137</td>
<td>110-139</td>
<td>113-143</td>
</tr>
<tr>
<td><strong>White cell count x10^{12}/L</strong></td>
<td>6.4-12.1</td>
<td>5.4-13.6</td>
<td>4.9-12.8</td>
<td>4.7-12.3</td>
<td>4.7-12.2</td>
</tr>
<tr>
<td><strong>Platelets x10^{12}/L</strong></td>
<td>270-645</td>
<td>205-553</td>
<td>214-483</td>
<td>205-457</td>
<td>187-415</td>
</tr>
<tr>
<td><strong>Neutrophils</strong></td>
<td>0.8-4.9</td>
<td>1.1-6.0</td>
<td>1.7-6.7</td>
<td>1.8-7.7</td>
<td>1.8-7.6</td>
</tr>
</tbody>
</table>

I have to be mindful with hygiene and I keep away from crowds. I’ve learnt to avoid touching my mouth, nose and eyes with my hands. I wash my hands frequently to decrease my chances of infection.
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-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.
It was such a scary thing to be told I had cancer. I now feel very positive about my future as improved treatments lead to a brighter outlook for people with lymphoma.

WHAT IS LYMPHOMA?

Lymphoma is the general term for cancers that develop in the lymphatic system. Lymphoma originates in developing lymphocytes (B-cells and T-cells), which have undergone a malignant 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 and eventually the immune system becomes weakened and can no longer function properly.

The World Health Organisation currently recognises 43 different sub-types of lymphoma. Five of these sub-types belong to a group of diseases called Hodgkin Lymphoma. All other sub-types are commonly grouped together and called non-Hodgkin Lymphomas.

Each year in Australia around 5,000 people are diagnosed with lymphoma making it the sixth most common type of cancer in this country. Around 4,200 of these people have non-Hodgkin’s lymphoma, which represents around 85% of all cases.

Lymphomas are seen in all age groups but they are more common in people over the age of 50. In children, non-Hodgkin Lymphoma and leukaemia are some of the most common types of cancer seen, but this number is far fewer than in the adult population. Lymphomas in children tend to grow quickly and they are often curable.

Significant advances are continually being made in the way we manage lymphomas. This means that with treatment, many people can now be cured. Many others who are treated remain disease-free and well for a long time.
WHAT CAUSES LYMPHOMA?

Many people who are diagnosed with lymphoma ask the question, “Why me?”

Naturally, they want to know what has happened to them or what they might have done to cause their disease. We do know that it is not contagious. You cannot ‘catch’ lymphoma by being in contact with someone who has it.

In most cases people who are diagnosed with lymphoma have no family history of the disease. Like many cancers, damage to special proteins that control the growth and division of cells may play a role in the development of lymphoma.

The following are certain factors which may put some people at a higher risk of developing this disease.

Immunosuppression

A small percentage of lymphomas occur in people whose immune system has been weakened (immunosuppressed) either by a viral infection such as human immunodeficiency virus (HIV) or as a result of drugs which affect the function of the immune system (immunosuppressants). These drugs are commonly used when someone has a heart, lung or other organ transplant.

Infection

In some cases, particularly in people who are immunosuppressed, infections with viruses such as Epstein-Barr virus (EBV) or the human T-cell leukaemia/lymphoma virus (HTLV-1) may damage developing lymphocytes and put people at a higher risk of developing lymphoma.

Chemicals

Some evidence suggests that farmers and other people who are exposed to high concentrations of agricultural chemicals such as pesticides and fertilizers may have a higher risk of developing lymphoma.

Lifestyle

Certain lifestyle factors appear to increase the risk of NHL including smoking (follicular lymphoma) and obesity (diffuse large B-cell lymphoma).
What are the signs and symptoms of lymphoma?

Some people do not have any symptoms when they are first diagnosed with 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.

Lymphoma commonly presents as a firm, usually 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 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:
- regular and frequent fevers
- excessive sweating, usually at night
- unintentional weight loss
- persistent fatigue and lack of energy
- generalised itching.

Some of these symptoms may also be seen in other illnesses, including viral infections. So, most people with these symptoms do not have 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, investigated and treated properly and in a timely fashion.

Sometimes lymphoma starts in the lymph nodes in deeper parts of the body like those found in the abdomen (causing bloating), or the lymph nodes in the chest (causing coughing, discomfort in the chest or difficulty breathing). When it is first diagnosed, lymphoma is commonly found in several different sites in the body at once. It can spread to any organ and commonly may involve the spleen, liver, brain or the bone marrow.
WHICH DOCTOR?

If your general practitioner (GP) suspects that you might have 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.

HOW IS 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 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. This is usually the only biopsy method that can give a definitive lymphoma diagnosis.

If the swollen gland is in your abdomen or pelvis, a laparoscopy (or ‘keyhole’ surgery) 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 LYMPHOMA

Lymphoma is not a single disease; in fact, there are 43 different sub-types of lymphoma.

These many different sub-types are broadly divided into the following two main groups:

**B-cell lymphomas** - those that arise from developing B-cells

**T-cell lymphomas** - those that arise from developing T-cells.

The majority of lymphomas (over 80%) are B-cell lymphomas.

When deciding how to treat your lymphoma it is important to know how fast it is likely to grow and cause problems in your body.

**Indolent lymphomas** - also called low-grade lymphomas, these can grow slowly and may cause few symptoms and may not need to be treated initially.

**Aggressive lymphomas** - also called intermediate-grade and high-grade lymphomas, these grow more quickly, may cause more severe symptoms and generally need to be treated soon after they are diagnosed.

Both the likely growth behaviour of your lymphoma and whether it belongs to the B-cell or T-cell group can be determined by examining the cells from your lymph node biopsy, under a microscope in the laboratory.
Below you will find some examples of B-cell and T-cell lymphomas. The more common types are written in bold text.

**B-Cell Lymphomas**
- Diffuse large B-cell lymphoma
- Follicular lymphoma
- Extramedullary marginal zone B-cell lymphoma (also called mucosa-associated lymphatic tissue lymphoma or MALT lymphoma)
- Chronic lymphocytic leukaemia/small lymphocytic lymphoma
- Mantle cell lymphoma
- Mediastinal (thymic) large B-cell lymphoma
- Burkitt's lymphoma/leukaemia
- Waldenström's Macroglobulinaemia (also called Lymphoplasmacytic lymphoma)
- Nodal marginal zone B-cell lymphoma
- Splenic marginal zone lymphoma

**T-Cell Lymphomas**
- Peripheral T-cell lymphoma
- Mycosis fungoides
- Sezary syndrome
- Angio-immunoblastic T-cell lymphoma
- Anaplastic large cell lymphoma
- Precursor T-lymphocyte leukaemia/lymphoma

**More information**

The current World Health Organisation’s classification system recognises 43 different sub-types of non-Hodgkin lymphoma. The various diseases are distinguished from each by:

1. Their cell of origin - lymphoma cells carry special markers like flags on their surface called antigens that identify them as having developed from either B- or T-cells.

2. The appearance of the cell under the microscope - for example, the size of the cells (small or large cell) and how ‘differentiated’ or mature they are. In general, the more immature cells are (those described as large cell, anaplastic or blastic cell lymphomas) the more aggressive in nature they tend to be, and therefore grow more quickly.

3. Some lymphomas are described according to the areas within the lymph node they are found (mantle cell lymphoma, marginal zone lymphoma), while others are described according to the distinct way in which the cells are arranged within the lymph node (e.g. follicular and diffuse large B-cell lymphoma).

4. The genetic (DNA) make-up of the cells - certain genetic abnormalities, such as missing or extra chromosomes (collections of DNA) may help to distinguish one type of lymphoma from another type.
Learn about your disease and become a partner with your medical team rather than a patient.

**Lymphoma or leukaemia?**
When lymphoma cells are found mostly within the blood and bone marrow, the cancer presents as leukaemia. When the affected cells are predominantly found in the lymphatic system however, the cancer almost always presents as lymphoma. In some cases the disease can present as either leukaemia or lymphoma and is therefore classified as both (i.e. leukaemia/lymphoma). Some people seem to have lymphoma first and then over time show signs that their disease is progressing into a type of leukaemia.

**Some common forms of lymphoma***

**Diffuse large B-cell lymphoma**
Diffuse large B-cell lymphoma (DLBCL) is the most common type of lymphoma and represents about 30% of all cases. It usually affects middle aged and elderly people but it can also affect children and young adults. In this type of lymphoma the normal structure of the lymph node is disrupted and the lymphoma cells have spread widely (diffusely) throughout the lymph node. This type of lymphoma is regarded as intermediate or high grade and without treatment tends to spread over weeks or months from the lymph node to other areas of the body including the skin, gut, central nervous system and bone. Treatment is effective in the majority of cases and many patients are cured.

**Follicular lymphoma**
Follicular lymphoma is another common type of lymphoma representing around 25% of all cases. Follicular lymphoma gets its name from the way in which the lymphocytes are arranged in clusters or circular structures called follicles, within the lymph node. This type of lymphoma is usually slow-growing, over months or years (indolent). It is usually well-controlled with treatment but like most indolent lymphomas, is not commonly curable.

* For more information on your particular type of lymphoma please contact the Leukaemia Foundation for a fact sheet.
Chronic lymphocytic leukaemia (CLL)/ small lymphocytic lymphoma (SLL)

CLL is the most common type of leukaemia in the Western world. It usually affects older people. This disease can present as either leukaemia (CLL) or lymphoma (SLL). Initially it tends to be an indolent disease, requiring little or no treatment for many years.

Mantle cell lymphoma

Mantle cell lymphoma is often more aggressive than the other small B-cell lymphomas and is usually widespread when it is first diagnosed.

Burkitt lymphoma

Burkitt lymphoma is a rare, high grade type of lymphoma. It can also present as leukaemia. Burkitt lymphoma produces a mass of lymphoma cells, often in the abdomen, and can spread very quickly (over days). It is usually treated with high doses of chemotherapy and is frequently cured.

Cutaneous T-cell lymphomas

Cutaneous T-cell lymphomas (including Mycosis fungoides and Sezary syndrome) primarily affect the skin and the lymph nodes. In the early stages these lymphomas are generally indolent. Redness of the skin and intense itching is common, and treatment may involve the use of creams, emollients, medications to help you stop itching, and ultraviolet light. Chemotherapy and radiotherapy may also be used in more advanced stage disease.

AIDS-related lymphoma

Lymphomas that occur in people with human immunodeficiency virus (HIV) tend to be aggressive and quite advanced when they are first diagnosed.

Central nervous system lymphoma

In the more high grade types of disease, lymphoma can spread from its original site to the brain and spinal cord. In the case of primary central nervous system lymphoma, the disease is only found in these areas. Treatment usually involves radiotherapy and chemotherapy that specifically targets the lymphoma in this area.
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 the 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.

It 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 with 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.

It is not a good idea to search the internet to try to find your own prognosis. There are so many factors that are unique to you that have an impact on your prognosis. Only your own treating doctor is in a position to provide information on the likely course of your disease. Finding ‘survival statistics’ online does not provide you with any context about the disease, where you fit within the large trajectory of outcomes within the disease, and may have little to do with your cancer experience. It often leads to unnecessary distress that could be alleviated by speaking directly with your doctor.

Curability of lymphoma depends on the particular sub-type. The vast majority of lymphomas respond well to therapy initially. The treatment for lymphoma continues to improve and many people remain disease-free and well for a long time. This is also known as being in remission. If your 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.

The thing I found hardest was telling my partner and my friends and family.
TREATMENT

The treatment chosen for your disease depends on several factors including the particular type of lymphoma you have, where it has spread within your body, your age and your general health.

Information gathered from thousands 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.

Treatment for lymphomas may involve the use of chemotherapy, radiotherapy, monoclonal antibodies, or combinations of these treatments. Peripheral blood stem cell transplantation may also be used.

Indolent lymphomas (low-grade)

Many low-grade lymphomas take years to grow, cause few (if any) symptoms, and do not necessarily need to be treated on diagnosis. In these cases the doctor may recommend regular checkups to carefully monitor your lymphoma and general health.

If the lymphoma is limited to a small group of lymph nodes (stage 1 or 2), radiotherapy alone may be able to cure some low-grade lymphomas, or control them for a long time. If the low-grade lymphoma is more widespread in the body, the decision to treat the disease or not depends on a number of factors such as: where the lymphoma has spread to, how large the areas of lymphoma are, if you are experiencing any symptoms of your lymphoma, and your general health.

If treatment is warranted, chemotherapy (either in tablet form or intravenously) and/or immunotherapy is usually given. This is very effective for the majority of people and puts many patients into a remission that lasts a variable length of time.
Immunotherapy refers to the administration of monoclonal antibodies such as rituximab (also known as MabThera). This has been shown to be effective when used alone or in combination with chemotherapy for B-cell lymphomas. Sometimes treatment with rituximab is continued after the chemotherapy has been stopped (maintenance therapy).

In some cases, low-grade lymphomas develop over time into more aggressive or high grade lymphomas requiring more aggressive treatment.

**Intermediate and high-grade lymphomas**

Intermediate-grade and high-grade lymphomas grow quickly, and treatment is needed when they are diagnosed. If these diseases respond well to chemotherapy they can sometimes be cured. Chemotherapy is usually combined with rituximab in B-cell lymphomas to give the best results.

**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, using more and different chemotherapy, or using more intensive or high-dose chemotherapy followed by a stem cell transplant.

**Palliative care**

If the disease cannot be cured, a decision is made to control symptoms and not to cure. The treatments may still involve milder forms of anti-cancer treatment (chemotherapy or less intensive radiotherapy) for your lymphoma. If you and your doctor decide not to continue with any anti-cancer treatment, there are still many things that can be done to help you to stay as healthy and comfortable as possible for some time. Palliative care is aimed at relieving any symptoms or pain you might be experiencing as a result of your disease or its treatment, rather than trying to cure or control it.

**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.
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.
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, R-CHOP chemotherapy is commonly used to treat lymphoma and involves the use of rituximab, cyclophosphamide, hydroxydaunomycin (doxorubicin), vincristine, and prednisone. R-CVP chemotherapy involves the use of rituximab, cyclophosphamide, vincristine and prednisone. Each drug targets the cancer from a different angle, making the combination of chemotherapy drugs more effective than a single drug in destroying the cancer.

Chemotherapy is usually given in several cycles (or courses) with a rest period of a few weeks in between each cycle. This is to allow the body to recover from the side-effects of chemotherapy. A typical chemotherapy regimen for lymphoma involves six to eight cycles of a combination of drugs, given every two or three weeks over a period of several months.

Improved results have been achieved by combining chemotherapy with immunotherapy like rituximab. Immunotherapy is a more recent treatment option for lymphoma and it works differently from other forms of cancer therapy. Rituximab is the first of these promising agents available.

Rituximab is one of a new group of treatments called ‘Targeted Therapies’ because it is specifically engineered to target lymphoma cells. Once antibodies bind to these cells, a patient’s own immune system is then able to recognise these cancer cells as foreign and kill them.

Rituximab specifically targets a protein called CD20, found only on the surface of mature B-lymphocytes. It does not affect other cells, which may explain why it is usually well-tolerated and has fewer side-effects than many other cancer therapies.
**How is chemotherapy given?**

There are many ways of giving chemotherapy. It is usually given through a vein (intravenously or IV) in your arm or hand, or in tablet form (orally). For lymphoma, chemotherapy may also be given intrathecally (into the spinal fluid) to prevent or treat CNS (central nervous system – brain and spinal cord) disease.

If you are having several cycles of 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. 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 many cases you do not need to stay in the hospital for chemotherapy. It is often given in the outpatients/day procedure department of the hospital and patients go home the same day. Sometimes however, depending on the type of chemotherapy being given and your general health, you may need to stay in hospital for a short while.
**Side-effects of chemotherapy**

Chemotherapy kills cells that multiply quickly, such as cancer cells. It also causes damage to fast-growing normal cells, including hair cells, and cells in your mouth, gut and bone marrow. 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 is 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 and doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you. Education sessions to make you more aware of the common effects of chemotherapy are offered at most treatment centres.

**Effects on the 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 white cells, platelets and red cells 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 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 that are contagious (for example colds, flu, chicken pox) and only eating food which has been properly prepared and cooked (low bacterial). 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 the blood). When your platelet count is very low you can bruise and bleed more easily.

During this time it is sensible to avoid sharp objects in your mouth such as chop bones or potato chips, as these can cut your gums. Using a soft tooth brush 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 you may become 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 red cell (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

» persistent pain, swelling, redness or pus anywhere on your body.

* A 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 you can try. 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.

**Share the burden so others can help you carry it and build you up when you don’t feel strong.**
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).

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.

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

For some people, the thought of losing their hair is very frightening. Hair loss is unfortunately a very common side-effect of chemotherapy and some forms of radiotherapy. However, it is 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 and wash it less frequently than what you normally would. Some people find it more comfortable to simply have a short haircut when they notice their hair starting to fall out.

**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.

*My company was very good to me and allowed me to work from home, encouraging and supporting me constantly.*
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 (like 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 eyebrows, eyelashes, and all other parts of the 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 Freecall them on **1800 650 960**.

**Fatigue**

Most people experience some degree of tiredness in the days and weeks following treatment. Getting plenty of rest and doing light exercise each day may help to make you feel better during this time. Getting outside 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.

You may need to prioritise the activities that are important to you and plan your day around these things. Pace yourself, and know that your energy levels can be different day to day.

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*I find the biggest side-effect on a day to day basis is tiredness and it is hard for people to understand why I need to rest and be in bed early. I look fine but I am extremely 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 non-Hodgkin lymphoma.

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 and varies from person to person depending on the site of their disease. Common radiation fields may include lymph nodes in the neck, chest, armpit, abdomen, groin or the spleen.

What is involved in radiotherapy?

Before you start radiotherapy, 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 weekday (Monday to Friday) over a few weeks. It is given in the radiotherapy 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 like your heart and lungs are shielded as much as possible to ensure that they are not affected by the treatment given. Radiotherapy is painless; 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 (on the site radiated), hair loss and fatigue. In general, 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 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 your skin by 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 area treated. These include the parotid or submandibular glands, which are situated at the top of the jawline in front of the ears. Parotitis causes dryness of the mouth and jaw pain which usually settles down within a few days once the inflammation subsides.

It was quite hard being diagnosed as a young person. I couldn’t do the things I enjoyed with my friends.
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 your own 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 people who have relapsed or are at high risk of relapse, and to those for whom standard (conventional) treatment has not worked.

Another type of transplant involves chemotherapy (and/or radiotherapy), followed by receiving stem cells collected from another person (allogeneic stem cell transplant). This type of transplant is quite different from an autologous transplant, and is generally reserved for circumstances where all other standard treatments and an autologous transplant have already been used.

* There are separate Leukaemia Foundation booklets called ‘Understanding Autologous Stem Cell Transplants’ and ‘Understanding Allogeneic Stem Cell Transplants’, which provide more details on these types of treatments.
Targeted therapies

Targeted therapies are special treatments that utilise our knowledge about lymphomas to direct the therapy more accurately to the lymphoma cells. One example of a targeted therapy is monoclonal antibody therapy which harnesses the power of the body’s immune system to fight the lymphoma.

A second type of targeted therapy is a molecular inhibitor. These new types of treatments are able to modify the chemical pathways inside the lymphoma cells in such a way that the cells are no longer able to grow and they eventually die.

Many of these targeted therapies are currently only available as part of clinical trials. Talk to your doctor about whether one of these clinical trials may be an option for you.

Side-effects of monoclonal antibody therapies

Side-effects vary depending on the type of biotherapy used. They are usually temporary and may include flu-like symptoms such as chills, fevers, aches and pains and weakness. Your doctor or nurse will explain any side-effects you might experience while you are having these treatments and how they can be managed.

Meeting with others going through these issues helps make it more of a shared experience rather than just an individual struggle.
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 regimen. 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. 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 like 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.

People who have a history of mental health challenges should talk to their doctor before taking steroids. Taking steroids may heighten feelings and may acutely impact on your mental state. Precautions should be taken to ensure your mental safety whilst taking steroid therapy.

Surgery
Diseased lymph nodes in lymphoma cannot effectively be removed with surgery, however you may require an operation at some point in your treatment to manage certain complications such as an enlarged spleen (splenectomy).
Complementary therapies

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

Complementary therapies should ‘complement’ or assist with recommended medical treatment for lymphomas. **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 lymphoma. It is also important to let your doctor or nurse know if you are using any complementary or alternative therapies including any herbal supplements in case they interfere with the effectiveness of chemotherapy or other treatment you may be having.

Nutrition *

A healthy and nutritious diet is important to help your body 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 dietitian who can advise you on planning a well-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 another Leukaemia Foundation booklet called ‘Eating well’
BODY IMAGE, SEXUALITY AND SEXUAL ACTIVITY

It is likely that the diagnosis and treatment of 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. Remember that most of these appearance changes are temporary and there are small changes you can make to the way you dress or apply makeup which can make you feel more attractive.

Allow yourself to get pampered; have a massage or buy a beautiful head scarf to lift your mood. This is the time to look after yourself and treat your body well.

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 activities such as gentle touching or cuddling your partner that you can do. 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 recommended that you or your partner do not become pregnant as some of the treatments given might harm the developing baby. Some research indicates that it may be wise not to become pregnant for a minimum of 12 months after the use of rituximab. As such you need to ensure that you and your partner use a suitable form of contraception.

Partners are sometimes afraid that sex might in some way harm the patient, however this is unlikely as long as the patient does not have a very low neutrophil count at the time, 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 be a particular person in your treating team who you trust and feel comfortable enough with to discuss such personal issues.
Potential Late Effects of Treatment

Many people enjoy long and healthy lives after being successfully treated for lymphoma. However sometimes, 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 then steps can be taken to correct it.

Radiotherapy to the chest and some chemotherapy drugs occasionally cause 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 late effects.

After your treatment has finished, drawing up a late effects plan with your doctor or nurse can help you to manage your ongoing wellness and will let you know what you will need to have regularly monitored in the future, and when.

I am really positive about the future. I ensure I am aware of what my body is telling me. My late effects care plan makes me feel my ongoing health is being monitored.
MAKING TREATMENT DECISIONS

Many people feel overwhelmed when they are diagnosed with a 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 a family member or a friend 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 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 is necessary or if you are unsure about any of the information you have been given.
People cope with a diagnosis of 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. On the other hand, people who do not currently require treatment may wonder if they are sick at all.

It is worth remembering that information can often help to take away the anxiety caused by 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 diseases like lymphoma. 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 request additional support from a mental health professional.
At first I thought seeking support meant that I was being weak. I now understand that seeking support was the first step for me taking control of my situation.

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. There may be a lymphoma support group near you. Contact the Leukaemia Foundation for more information.

The Leukaemia Foundation is here to provide you and your family with information and support. The Leukaemia Foundation’s support staff can assist you in many ways. Contact details are provided on the back of this booklet.
### USEFUL INTERNET ADDRESSES

**Leukaemia Foundation**  
www.leukaemia.org.au

**American Cancer Society**  
www.cancer.org

**Australian Bone Marrow Donor Registry**  
www.abmdr.org.au

**Cancer Council of Australia**  
www.cancer.org.au

**ClinicalTrials.gov**  
www.clinicaltrials.gov

**Leukemia & Lymphoma Society (USA)**  
www.lls.org

**Bloodwise (UK)**  
www.bloodwise.org.uk

**Look Good … Feel Better program**  
www/lgfb.org.au

**Lymphoma Australia**  
www.lymphoma.org.au

**Lymphoma Association UK**  
www.lymphomas.org.uk

**Lymphoma Coalition**  
www.lymphomacoalition.org

**Lymphoma Foundation Canada**  
www.lymphoma.ca

**Lymphoma Research Foundation (USA)**  
www.lymphoma.org

**National Cancer Institute (USA)**  
www.cancer.gov/cancerinfo

**Redkite – Practical support for young people with cancer**  
www.redkite.org.au
Alopecia
Hair loss. This is a side-effect of some kinds of chemotherapy and radiotherapy. It is usually temporary.

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

Antibody
Naturally-produced substance 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.

B-lymphocyte
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. Active or red bone marrow contains stem cells from which all blood cells are made.

Blood count
A routine blood test that measures the number and type of cells circulating in the blood. Also called a full blood count (FBC).

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.

Antigens
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.

Antiemetic
A drug which prevents or reduces feelings of sickness.
Cannula
A plastic tube which can be inserted into a vein to allow fluid to enter the bloodstream.

Central venous catheter (CVC)
A line or 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 (mucositis). Nausea and vomiting are also common, but nowadays largely preventable with modern anti-nausea medication. 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 three dimensional (3D) images of cross sections of the body.

Cure
This means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

Diaphragm
A layer of muscle under the ribs that separates the stomach from the chest.

Disease progression
When the disease gets worse despite treatment.

Echocardiogram
A special ultrasound scan of the heart.
Electrocardiogram (ECG)
Electrical trace of the heart.

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
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 lymphoma
A fast-growing lymphoma.

Hodgkin lymphoma
A type of lymphoma (cancer of the lymphatic system). All other types of lymphoma come under the heading of non-Hodgkin’s lymphoma.

Hypothyroidism
A reduction in the normal function of the thyroid gland.

Immune system
The body’s defence system against infection and disease.

Immunocompromised
When the function of the immune system is reduced.

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 they can cause very high abnormal white cell counts.

**Localised disease**
Disease that is confined to a small area or areas.

**Low-grade lymphoma**
A slow-growing lymphoma.

**Lymph nodes or glands**
Structures found throughout the body, for example in the neck, groin, armpit 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 vessels, similar to blood vessels, that branch out into all the tissues of the body. These vessels carry lymph, a colourless watery fluid that carries 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 blood 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 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 (see cancer).

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

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

Neutrophils
Neutrophils are the most common type of white blood cell. They are needed to mount an effective fight against infection.

Non-Hodgkin lymphomas
The name given to a group of lymphomas (cancer of the lymphatic system) that differs in important ways from Hodgkin’s lymphoma and are classified according to the appearance of the cancer cells under the microscope. Non-Hodgkin’s lymphoma can be slow growing (low grade) or fast growing (intermediate or high grade) and may be treated in a variety of ways. They are also called B-cell and T-cell lymphomas.

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

**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**
This means that the disease is not responding to treatment.

**Remission**
When there is no evidence of disease in the body.

**Spleen**
The spleen is found high in the abdomen on the left-hand side and cannot normally be felt on examination unless it is enlarged. It is an organ that is part of the blood system and is a specialized collection of lymphoid and haematopoietic tissue. It plays a minor role in the immune system and contributes to the destruction of red blood cells, white blood cells and platelets at the end of their life-span. It is often enlarged in diseases of the blood: this is known as splenomegaly.

**Splenomegaly**
Enlargement of the spleen.
Stable disease
When the disease is stable it is not getting any worse or any better 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 primitive blood cells that can give rise to 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.

T-lymphocyte
A type of white cell involved in controlling immune reactions.

Thymus
A gland found behind the breast bone 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 cells of the immune system that protect the body against infection. There are five main types of white blood cells: neutrophils, eosinophils, basophils, monocytes and lymphocytes.

X-ray
A form of radiation used in diagnosis and treatment.
MAKING A DONATION

The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life. It exists only because of the generous and ongoing support of the Australian community.

How can I give?

ONLINE leukaemia.org.au

PHONE 1800 620 420

POST (complete this form or enclose cheque/money order and return)

The Leukaemia Foundation, Reply Paid 9954 in your capital city

Name

Address

Postcode

Phone

Mobile

Email

I enclose my gift of (please tick box)

- $30
- $50
- $75
- $100
- $250
- Other $

My cheque/money order made payable to the Leukaemia Foundation is enclosed.

I wish to pay with my credit card and my details are included below:

- Visa
- MasterCard
- Diners
- Amex

Card Number

Expiry Date  MM  YY

Cardholder’s Name

Signature

Your privacy is important to us. That is why we treat your personal information with confidence. To learn more about how and why we collect and use any personal or sensitive information about you, please view our Notification Statement at www.leukaemia.org.au/privacy
PLEASE SEND ME A COPY OF THE FOLLOWING BOOKLETS:

- Leukaemia, Lymphoma, Myeloma, MDS, MPN and related blood disorders
- Acute Lymphoblastic Leukaemia in Adults (ALL)
- Acute Lymphoblastic Leukaemia in Children (ALL)
- Acute Myeloid Leukaemia (AML)
- Amyloidosis
- Chronic Lymphocytic Leukaemia (CLL)
- Chronic Myeloid Leukaemia (CML)
- Hodgkin Lymphoma
- Non-Hodgkin Lymphoma (NHL)
- Myelodysplastic Syndrome (MDS)
- Myeloma
- Myeloproliferative Neoplasms (MPN)
- Living Well
- Living with Leukaemia, Lymphoma, Myeloma, MDS, MPN and related blood disorders
- Allogeneic Stem Cell Transplants (also called Bone Marrow Transplants)
- Autologous Stem Cell Transplants
- Young Adults with a Blood Cancer
- My Haematology Diary

Books for children:
- Tom has Lymphoma
- Joe has Leukaemia
- Ben’s Stem Cell Transplant
- Jess’ Stem Cell Donation

Or information about:
- The Leukaemia Foundation’s Support Services
- Workplace Giving
- Monthly giving program
- National fundraising campaigns
- Volunteering
- Receiving our newsletters
- Leaving a gift in my will

Name
Address
Postcode
Phone
Mobile
Email

POST TO The Leukaemia Foundation, Reply Paid 9954 in your capital city
PHONE 1800 620 420 EMAIL info@leukaemia.org.au
FURTHER INFORMATION ONLINE leukaemia.org.au
This information booklet is produced by the Leukaemia Foundation and is one in a series on leukaemia, lymphoma, myeloma, MDS, MPN and related blood disorders.

Copies of this booklet can be obtained from the Leukaemia Foundation by contacting us.

The Leukaemia Foundation is a not-for-profit organisation that depends on donations and support from the community. Please support the Leukaemia Foundation today.

June 2017

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