Understanding Non-Hodgkin Lymphoma

A guide for people with cancer, their families and friends

For information & support, call 13 11 20
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Understanding Non-Hodgkin Lymphoma is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.


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We would also like to thank the health professionals and consumers who have worked on previous editions of this title.

Note to reader
Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council NSW excludes all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council NSW
Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help beat cancer, visit cancercouncil.com.au or phone 1300 780 113.

Cancer Council NSW
153 Dowling Street, Woolloomooloo NSW 2011
Telephone 02 9334 1900 Facsimile 02 8302 3500
Email feedback@nswcc.org.au Website cancercouncil.com.au
ABN 51 116 463 846
Introduction

This booklet has been prepared to help you understand more about non-Hodgkin lymphoma.

Many people feel shocked and upset when told they have non-Hodgkin lymphoma. We hope this booklet will help you, your family and friends understand how it is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed
This information was developed with help from a range of health professionals and people affected by non-Hodgkin lymphoma. It is based on clinical practice guidelines for non-Hodgkin lymphoma.¹

If you or your family have any questions, call Cancer Council 13 11 20. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.
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Cancer is a disease of the cells, which are the body’s basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don’t grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (a process known as angiogenesis).

In non-Hodgkin lymphoma, the cancer cells usually affect and enlarge the lymph nodes at one or more lymph node sites around the body (see page 7). The cancer cells can spread to other organs,
particularly the spleen and liver. Occasionally, the cancer can spread to the brain and spinal cord (central nervous system).

In cancers that can affect the blood and bone marrow, like non-Hodgkin lymphoma, abnormal cells multiply in such a way that they can crowd the bone marrow and reduce its ability to make normal blood cells.

**How cancer starts**

- **Normal cells**
  - Normal cells
  - Boundary
  - Lymph vessel
  - Blood vessel

- **Abnormal cells**
  - Abnormal cells
  - Angiogenesis – tumours grow their own blood vessels

- **Abnormal cells multiply**

- **Malignant or invasive cancer**
The lymphatic system

Non-Hodgkin lymphoma is a cancer that starts in the lymphatic system. The lymphatic system is a key part of the immune system, which helps protect the body against disease and infection.

**Lymph vessels**
The lymphatic system includes a large network of thin tubes called lymph vessels that are found throughout the body and in a number of organs, such as the spleen, liver, thymus gland and bone marrow.

Lymph vessels carry a clear fluid called lymph, which travels to and from the tissues in the body before being emptied into the bloodstream. Lymph fluid contains white blood cells called lymphocytes, which help fight infection. The two main types of lymphocytes, B-cells and T-cells, are produced in the bone marrow. Non-Hodgkin lymphoma starts in these B-cells and T-cells.

**Lymph nodes**
Along the lymph vessels is a network of small, bean-shaped structures called lymph nodes or glands. Lymph nodes are found throughout the body, including in the neck, underarms, chest, abdomen and groin.

Lymphocytes in the lymph nodes clean the lymph fluid as it passes through the body by removing and destroying bacteria, viruses and other harmful substances. When germs become trapped in the lymph nodes, the lymph nodes swell, which is a sign that the lymphocytes have multiplied to fight off the germs. For example, the glands in your neck may swell when you have a sore throat.
Anatomy of the lymphatic system

- Tonsils
- Lymph vessels
- Diaphragm
- Spleen
- Liver
- Thymus gland
- Lymph nodes
Other parts of the lymphatic system

The lymphatic system also includes the following organs and tissues:

**Spleen** – The spleen is found on the left side of the abdomen, under the ribs. It stores lymphocytes, filters waste products from the blood, and destroys old cells, abnormal cells and bacteria.

**Thymus gland** – This is found inside the rib cage, behind the breastbone. The thymus gland helps produce lymphocytes.

**Tonsils** – The tonsils are a collection of lymphatic tissue at the back of the throat that traps inhaled or ingested germs.

**Bone marrow** – This is the soft, spongy material inside the bones. Bone marrow produces three types of blood cells: oxygen-carrying red blood cells; infection-fighting white blood cells, including lymphocytes; and platelets, which help the blood to clot.

Different types of lymphoma

There are two main types of lymphoma: non-Hodgkin lymphoma and Hodgkin lymphoma. These two types look different when the diseased cells are examined under a microscope. For a free booklet about Hodgkin lymphoma, call Cancer Council 13 11 20, or visit cancercouncil.com.au to download a digital version.
Q: What is non-Hodgkin lymphoma?
A: Non-Hodgkin lymphoma is a type of lymphoma, which is a general term for cancers that develop in the lymphatic system. It is sometimes called non-Hodgkin’s lymphoma.

When types of white blood cells called lymphocytes become damaged, they grow abnormally and multiply uncontrollably, causing enlarged lymph nodes and painless lumps called tumours. As these damaged lymphocytes replace normal lymphocytes, the body’s immune system becomes less able to fight infections. This is how non-Hodgkin lymphoma develops.

Non-Hodgkin lymphoma can occur in one lymph node, a group of lymph nodes, or an organ such as the liver or spleen. It is sometimes found in several parts of the body at the same time.

Q: What types are there?
A: There are many different types of non-Hodgkin lymphoma. It can be classified according to whether the cancer started in the B-cells or T-cells of lymphocytes. The table on the next page describes some of the more commonly diagnosed types of non-Hodgkin lymphoma.

Non-Hodgkin lymphoma can also be classified as either low grade (slow-growing) or high grade (fast-growing) – see page 27 for more information.
<table>
<thead>
<tr>
<th><strong>B-cell lymphomas</strong></th>
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<tbody>
<tr>
<td><strong>diffuse large B-cell</strong></td>
<td>a fast-growing cancer that starts in lymph nodes in the neck, armpit or groin</td>
</tr>
<tr>
<td><strong>follicular</strong></td>
<td>cancer cells grow slowly in lymph nodes in circular groups called follicles</td>
</tr>
<tr>
<td><strong>small lymphocytic</strong></td>
<td>a slow-growing cancer that is similar to chronic lymphocytic leukaemia</td>
</tr>
<tr>
<td><strong>mantle cell</strong></td>
<td>develops in the outer edge (mantle zone) of B-cells in the lymph nodes</td>
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<thead>
<tr>
<th><strong>T-cell lymphomas</strong></th>
<th></th>
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<tbody>
<tr>
<td><strong>precursor T-lymphoblastic</strong></td>
<td>starts in immature (precursor) T-cells in the lymph nodes and the spleen</td>
</tr>
<tr>
<td><strong>peripheral T-cell</strong></td>
<td>often occurs as widespread enlarged, painless lymph nodes in the neck, armpit or groin</td>
</tr>
<tr>
<td><strong>cutaneous T-cell</strong></td>
<td>primarily affects the skin and starts as red, scaly patches or raised bumps that can be itchy</td>
</tr>
</tbody>
</table>
Q: What are the risk factors?
A: In most cases of non-Hodgkin lymphoma, the cause is unknown. However, there are some factors that can increase the risk of the disease:

Immune system deficiency – The immune system is weakened in people with HIV and those taking medicines called immunosuppressants. These include drugs to treat HIV and those that are given to people after an organ transplant. People with autoimmune diseases, such as rheumatoid arthritis and coeliac disease, also have a weakened immune system.

Infections – Some infections can slightly increase the risk of non-Hodgkin lymphoma. These include HTLV-1 (human T-lymphotropic virus 1), Helicobacter pylori, Epstein-Barr virus infection and human herpesvirus 8.

Many people with known risk factors don’t develop non-Hodgkin lymphoma, and some people who do get it have no known risk factors. Non-Hodgkin lymphoma is not contagious.

Q: How common is it?
A: Each year in NSW, about 1400 people are diagnosed with non-Hodgkin lymphoma. Most cases of non-Hodgkin lymphoma occur in adults aged 60 and older. However, it can also occur in young adults and children.
Q: What are the symptoms?

A: Non-Hodgkin lymphoma can cause different symptoms depending on where it is located in the body. These symptoms include:

- painless swelling of a lymph node (e.g. in the neck, underarm or groin)
- unexplained and regular fevers
- excessive sweating, particularly at night
- loss of appetite
- unintentional weight loss
- persistent tiredness (fatigue)
- itchy skin.

Sometimes non-Hodgkin lymphoma starts in lymph nodes in deeper parts of the body, such as the abdomen (causing bloating) or the chest (causing coughing, discomfort and difficulty breathing).

Symptoms of non-Hodgkin lymphoma are common to many conditions, such as the flu or a virus. If you are concerned, make an appointment to see your general practitioner (GP).
Diagnosis

If your GP suspects that you have non-Hodgkin lymphoma, they will ask you about any symptoms you may have, possible risk factors, your medical history and your family’s medical history. They will also give you a physical examination to check your lymph nodes for swelling and will examine your throat, tonsils, neck, abdomen, underarms and groin.

Your GP may organise further tests or refer you to a specialist for tests to:
• check your overall health
• find out whether you have cancer
• see whether the cancer has spread.

Biopsy
The only way to confirm a diagnosis of non-Hodgkin lymphoma is to remove the enlarged lymph node, or part of it, so a pathologist can examine it under a microscope. This procedure is called a biopsy and it can be done in different ways according to your doctor’s recommendation:

**Excision biopsy** – You will be given a local or general anaesthetic, depending on the location of the lymph node. The doctor will cut through the skin to remove the whole lymph node and then close the wound with temporary stitches. The stitches will be removed about a week later. An excision biopsy may be done as an outpatient procedure. If the lymph node is deep inside your body (e.g. in the abdomen or chest), you may have to stay in hospital for a few days.
**Needle biopsy** – You will be given a local anaesthetic to numb the area of your body where the lymph node is located. The doctor will use a needle to remove a small amount of tissue from the lymph node. This procedure is done as an outpatient and usually takes 30–60 minutes.

The results of the biopsy will be available in about a week.

**Further tests**
If the biopsy shows that you have non-Hodgkin lymphoma, it is important to find out whether it has spread to other parts of your body. This process is called staging and it helps your doctors to decide on the best treatment for you. See pages 20–21 for more information about the stages of non-Hodgkin lymphoma.

The following pages describe tests that are commonly used to help stage non-Hodgkin lymphoma. You will probably not need to have all of these tests – most people will have blood tests (see opposite) and some imaging tests (see pages 16–18).

Some tests may be repeated during or after treatment to check your health and how well the treatment is working.

Waiting for test results can be an anxious time. It may help to talk about your feelings to a friend or family member, or you can call Cancer Council 13 11 20 to speak to a health professional.
Blood tests
Your doctor will take a sample of your blood to check your kidney and liver function. They will take further blood samples to check your blood counts, which measure the different levels of red blood cells, white blood cells and platelets in the blood. Low blood counts may indicate that the cancer has spread to the bone marrow.

<table>
<thead>
<tr>
<th>Blood cell levels and symptoms</th>
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<tbody>
<tr>
<td>low levels of red blood cells</td>
</tr>
<tr>
<td>can cause anaemia, which may make you look pale and feel tired, breathless and dizzy</td>
</tr>
<tr>
<td>low levels of white blood cells</td>
</tr>
<tr>
<td>may make you more likely to get infections and make it more difficult to get rid of infections</td>
</tr>
<tr>
<td>low platelet levels</td>
</tr>
<tr>
<td>can cause you to bruise easily, have frequent nosebleeds, or have prolonged bleeding from cuts</td>
</tr>
</tbody>
</table>

Bone marrow biopsy
This biopsy can show if there are any lymphoma cells in the bone marrow. It is usually done as an outpatient procedure in hospital.

Your doctor will give you a local anaesthetic, then insert a needle into your pelvic bone. They will remove a small amount of fluid and a very small piece of bone for examination.
The needle can cause some discomfort when it is inserted into the pelvic bone. This will last for only a few seconds. If you find that the procedure is causing you too much discomfort, ask your doctor for some extra pain relief. The bone marrow biopsy will take about 30 minutes.

**Imaging tests**

You will usually have at least one of the tests described below:

**CT scan** – A CT (computerised tomography) scan uses x-ray beams to create a detailed three-dimensional picture of the inside of the body. To check whether the cancer has spread, your chest, abdomen and pelvis will be scanned.

Before the scan, a special dye will be injected into a vein to make the pictures clearer. This may make you feel hot all over and leave a strange taste in your mouth for a few minutes.

The CT scanner is large and round like a doughnut. You will lie on a table that moves in and out of the scanner. The scan is painless but can be noisy and takes 30–60 minutes. Most people can go home as soon as the scan is over.

The dye used in a CT scan usually contains iodine. If you have had an allergic reaction to iodine or dyes during previous scans, let the person performing the scan know in advance. You should also tell the doctor if you’re diabetic, have kidney disease or are pregnant.
**PET scan** – A PET (positron emission tomography) scan is a specialised imaging test. Sometimes it is done in combination with a CT scan.

Before the PET scan, you will be injected with a glucose (sugar) solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more glucose solution than the normal cells do.

You will be asked to sit quietly for 30–60 minutes while the glucose moves around your body, then you will be scanned. While it may take a few hours to prepare for a PET scan, the scan itself takes only about 30 minutes.

**Ultrasound** – An ultrasound uses soundwaves to create a picture of the internal organs. This test is most commonly used to help find swollen lymph nodes or other lumps in the body.

A gel will be spread over your skin and a small device called a transducer passed over the area. The transducer creates soundwaves. When soundwaves meet something dense, such as an organ or tumour, they produce echoes. A computer turns the echoes into a picture on a computer screen. This test is painless and takes only a few minutes.

**MRI scan** – An MRI (magnetic resonance imaging) scan uses magnetism and radio waves to create detailed pictures of a particular area inside the body. It is not commonly used to diagnose non-Hodgkin lymphoma.
As with a CT scan, a special dye may be injected into a vein before the MRI to help make the pictures clearer. During the scan, you will lie on a table that slides into a metal cylinder. The machine makes a series of bangs and clicks and can be quite noisy.

The test is painless, but some people feel anxious lying in the cylinder. If you feel uncomfortable in confined spaces (claustrophobic), let your doctor or nurse know, as they may be able to give you headphones, suggest breathing techniques, or offer you a mild sedative to make you feel more relaxed.

The MRI scan takes 30–60 minutes, and you will be able to go home when it is finished. Let your doctor know if you have a pacemaker or another type of metal object in your body, as you may not be able to have an MRI scan.

Some people who are being tested for non-Hodgkin lymphoma also have an x-ray to check for enlarged lymph nodes in the chest.

**Lumbar puncture (spinal tap)**

A lumbar puncture allows the doctor to examine the fluid that protects the brain and spinal cord (the central nervous system). This procedure will help the doctor to determine whether there are lymphoma cells within the central nervous system. This is rare, so most people with non-Hodgkin lymphoma will not need to have a lumbar puncture.
If you do have a lumbar puncture, you will be placed in a curled position on your side and given a local anaesthetic. A thin needle will be inserted into your lower back to remove some fluid from the space between your backbones (spine).

You may feel some discomfort during a lumbar puncture. Tell your doctor if you feel any discomfort or pain, as they may be able to give you more anaesthetic.

After the procedure, you may have to lie on your back for a short time to help prevent the onset of a headache. If you do get a headache, check with your doctor whether you can take pain-relieving medicine. A lumbar puncture can also cause nausea, but this will usually ease within a few hours.

**Prognosis**

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease. Instead, your doctor can advise you on issues that are commonly experienced by people with the same type of non-Hodgkin lymphoma as you.

While some people with non-Hodgkin lymphoma may go into complete remission after treatment (when symptoms and signs of cancer disappear), others may experience multiple episodes (recurrences) of the disease, meaning they go in and out of remission over several years.
**Stages of non-Hodgkin lymphoma**

Staging describes how far the cancer has spread. Your doctor will discuss your stage with you in more detail.

**Stage I** – One lymph node area is affected. This is either above or below the diaphragm.

**Stage II** – Two or more lymph node areas are affected, either above or below the diaphragm.

**Stage III** – Lymph node areas both above and below the diaphragm are affected.

**Stage IV** – Lymphoma is in the lymph nodes and has also spread to organs (e.g. liver, lungs) or to bones.
Staging
The tests described on pages 14–19 help your doctors to determine the stage of the cancer and the appropriate treatment for you. The diagram opposite describes the different stages of non-Hodgkin lymphoma.

As well as a number, each stage is assigned a letter according to whether you are experiencing specific symptoms. ‘A’ means you have none of the usual symptoms of non-Hodgkin lymphoma; ‘B’ means you have some symptoms, such as unexplained fevers and night sweats.

Which health professionals will I see?
Your GP may arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a haematologist, who will organise further tests and advise you about treatment options.

A haematologist typically diagnoses and treats non-Hodgkin lymphoma, often with chemotherapy and monoclonal antibody therapy (see pages 28–32 for more information). Sometimes, a medical oncologist will oversee treatment instead.

You will probably be cared for by a range of health professionals who specialise in different aspects of your treatment. A list of people who may make up this multidisciplinary team (MDT) is on the next page.
<table>
<thead>
<tr>
<th>Health professional</th>
<th>Role</th>
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<tbody>
<tr>
<td>haematologist</td>
<td>specialises in diagnosing and treating diseases of the lymphatic system, blood and bone marrow</td>
</tr>
<tr>
<td>medical oncologist</td>
<td>prescribes and coordinates the course of chemotherapy; in some cases, is the main treating specialist</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>prescribes and coordinates the course of radiotherapy</td>
</tr>
<tr>
<td>radiation therapist</td>
<td>plans and delivers radiation treatment</td>
</tr>
<tr>
<td>cancer care coordinator, clinical nurse consultant</td>
<td>support patients and families during treatment; liaise with other members of the health care team</td>
</tr>
<tr>
<td>nurses</td>
<td>help administer drugs; provide care, information and support throughout all stages of treatment</td>
</tr>
<tr>
<td>dietitian</td>
<td>recommends an eating plan to follow during treatment and recovery</td>
</tr>
<tr>
<td>pharmacist</td>
<td>dispenses medicines and provides advice about drugs, dosage and side effects</td>
</tr>
<tr>
<td>social worker, psychologist</td>
<td>provide emotional support</td>
</tr>
<tr>
<td>physiotherapist, occupational therapist</td>
<td>help with physical or practical issues</td>
</tr>
</tbody>
</table>
Key points

• If your GP suspects that you have non-Hodgkin lymphoma, they will carry out a physical examination to check your lymph nodes for swelling.

• A biopsy is the only way to confirm a diagnosis of non-Hodgkin lymphoma. This is when an enlarged lymph node, or part of it, is removed for examination under a microscope.

• If the biopsy shows that you have non-Hodgkin lymphoma, you will have further tests to find out whether the cancer has spread. This process is called staging and helps your doctors to determine the most appropriate treatment for you.

• Blood tests can check how well your liver and kidneys are functioning. A blood count involves checking the number of red blood cells, white blood cells and platelets.

• You may need a bone marrow biopsy. This is when a needle is inserted into the pelvic bone to withdraw a small amount of fluid and a small piece of bone for examination.

• Many people will also have a CT scan and PET scan. Other diagnostic tests you may have include ultrasound, MRI scan and x-ray.

• Your doctor will talk to you about your prognosis, which is the expected outcome of a disease. It’s not possible to predict the exact course of the cancer.

• People with non-Hodgkin lymphoma can go into complete remission or may experience multiple episodes during their lifetime.
Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that’s based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask for further explanation – see page 50 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.
A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor’s recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by the first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of Understanding Clinical Trials and Research, or visit australiancancertrials.gov.au.
When planning your treatment, your doctor will consider the type of non-Hodgkin lymphoma you have, the stage, your age and general health, and your preferences.

The aim of treatment is to control the cancer so you go into remission. This is when the symptoms and signs of cancer reduce or disappear. Remission may last for a long period of time until the non-Hodgkin lymphoma becomes active again and further treatment is required. This pattern of remission and recurrence may repeat several times. Remission can also be permanent, which is when repeated tests show that no cancer is present.

**Watchful waiting**

If you are diagnosed with low-grade non-Hodgkin lymphoma (see opposite), you may not have treatment straightaway, but instead have regular check-ups to monitor the cancer. This approach is called watchful waiting.

Having treatment earlier than necessary can cause unpleasant side effects. It can also make your body resistant to treatment, so if you need it later, it may not work as well. Many people with untreated low-grade non-Hodgkin lymphoma continue their usual daily activities for many years.

Some people find watchful waiting difficult to accept. You might prefer to have treatment immediately. If you feel uncomfortable with watchful waiting, speak with your medical team. They may be able to put you in touch with someone who has had a similar experience.
Low-grade and high-grade non-Hodgkin lymphoma

One of the most important factors your doctors will take into account when deciding on treatment is whether you have low-grade (slow-growing) or high-grade (fast-growing) non-Hodgkin lymphoma.

Low-grade non-Hodgkin lymphoma – This grows very slowly and usually causes few symptoms because there is little change in the cancer over time.

If you are diagnosed with low-grade non-Hodgkin lymphoma, your doctor may decide that you don’t need treatment initially, but will monitor your health with regular check-ups and blood tests. This is called watchful waiting.

If there is a change or growth in the cancer that causes symptoms and other warning signs to appear, your doctor will recommend treatment, usually with chemotherapy (see pages 28–31). You may also have monoclonal antibody therapy (page 32) and radiotherapy (pages 32–34).

High-grade non-Hodgkin lymphoma – Doctors may call this aggressive non-Hodgkin lymphoma. It grows much faster than low-grade non-Hodgkin lymphoma and needs to be treated as soon as possible to have the best chance of destroying the cancer and causing remission.

Chemotherapy is the main treatment for high-grade non-Hodgkin lymphoma. You may be given chemotherapy initially and then have another type of treatment. This may include monoclonal antibody therapy, radiotherapy or a stem cell transplant. See pages 28–40 for more information about these treatments.
**Chemotherapy**

Chemotherapy is the use of drugs to kill cancer cells or slow their growth. Treatment is usually given as a combination of drugs. While each person’s schedule varies, generally chemotherapy is given over a few days, followed by a rest period of a few weeks. Treatment will be spread over 3–6 months.

For non-Hodgkin lymphoma, chemotherapy is often combined with other treatments, such as monoclonal antibody therapy (see page 32) or steroid therapy (pages 35–36). It is also sometimes given as palliative treatment (page 40).

Chemotherapy is given in tablet form or via an injection into the veins (intravenously). Intravenous treatment can be given through a drip or a device called a line or tube (see opposite). Occasionally, chemotherapy is given via a lumbar puncture (see pages 18–19). This is called intrathecal chemotherapy, and it is done to prevent or treat non-Hodgkin lymphoma in the brain or spinal cord.

Many people have chemotherapy as an outpatient, although at times you may need a short stay in hospital.

Some treatments for non-Hodgkin lymphoma can cause infertility, meaning you will no longer be able to have children. If having children is important to you, ask your doctor before treatment starts about whether there are options for preserving your fertility, such as storing sperm, eggs or embryos.
Throughout the treatment, you will be closely monitored by your doctor and you will have tests to see how the chemotherapy drugs are working. Chemotherapy treatment may be repeated several times until tests show that the cancer is in remission.

**Side effects of chemotherapy**
Chemotherapy drugs can harm healthy, fast-growing cells, such as the cells in your hair, mouth and blood. This can cause side effects such as hair loss, mouth sores, tiredness and nausea. These side effects can make it hard for you to function as you normally would.

### Types of intravenous lines

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PICC (peripherally inserted central catheter)</td>
<td>A thin tube that can stay in place for a long period of time. A PICC is inserted into a vein in the arm.</td>
</tr>
<tr>
<td>port-a-cath (port)</td>
<td>A small device with a dome-shaped opening (port) that is surgically inserted beneath the skin in the chest or arm. A tube called a catheter connects the port to a vein so fluids can be passed into the body.</td>
</tr>
<tr>
<td>central line (central venous catheter or CVC)</td>
<td>A thin tube with several openings that is inserted into a vein in the neck or chest.</td>
</tr>
<tr>
<td>cannula</td>
<td>A small, hollow plastic tube that is inserted into the hand or arm.</td>
</tr>
</tbody>
</table>
During chemotherapy, you can continue to work and carry out your daily activities, but you may need extra rest when you feel tired. Discuss any side effects you experience with your doctor or nurses. Most side effects will be temporary. Your health care team can give you medicine to help relieve some symptoms.

For more information about chemotherapy and its side effects, call Cancer Council 13 11 20, or visit cancercouncil.com.au to download a digital version of *Understanding Chemotherapy*.

**Heart scans**
Some types of chemotherapy can affect the way your heart works. You may have one of the following scans before, during or after chemotherapy treatment to test your heart function.

**Echocardiogram** – This is also called a cardiac echo or cardiac ultrasound. A few small, sticky patches called electrodes will be placed on your chest and gel spread over the area. The person performing the scan will use a small, paddle-shaped device that uses soundwaves to create pictures of your heart. The pictures will show up on a computer screen. You may be asked to hold your breath at times. This painless test can take up to an hour.

**Gated heart pool scan** – A small amount of blood will be taken from one of your veins, mixed with radioactive material and re-injected into you. The radioactive material can be seen on a computer screen as it pumps through your heart. The scan takes about 45 minutes and the radiation will leave your body within a few hours.
Taking care with infections

During chemotherapy, colds and flu may be easier to catch and harder to fight off, and scratches and cuts may become infected more easily. This is because the drugs reduce your white blood cell levels, making it harder for your body to fight infections.

Try to avoid crowded public places, and ask relatives or friends with a cold or the flu to wait until they are well before visiting. This may not be practical for the people you live with, so try to avoid close contact if they are unwell.

To prevent the spread of infections, remember to wash your hands with soap and water before preparing food and eating, and after using the toilet.

Take extra care to avoid food poisoning. Try to eat freshly cooked or prepared foods, and wash fruits and vegetables well before eating.

See your doctor if you are unwell during chemotherapy, particularly if you have a cold. Contact your doctor or go to the nearest hospital emergency department immediately if you experience one or more of the following symptoms:

- a fever of 38°C or higher
- chills or shivering
- sweating, especially at night
- a burning feeling when urinating
- a severe cough or sore throat
- vomiting that lasts more than a few hours
- unusual bruising or bleeding, such as nosebleeds, blood in your urine or black bowel motions
- severe abdominal pain, constipation or diarrhoea
- tenderness, redness or swelling around the site of the intravenous chemotherapy device
- prolonged faintness or dizziness and a rapid heartbeat.
Monoclonal antibody therapy
This is a type of biological therapy. Biological therapies or biotherapies are medicines made from synthetic (artificial) versions of chemicals that occur naturally in the body.

Monoclonal antibody therapy uses a synthetic version of immune system proteins called antibodies, which are part of the body’s natural defence against infection. These synthetic antibodies target and attach to cancer cells. This makes it easier for the body’s immune system to find and destroy these cells.

The therapy is given intravenously, usually as an outpatient. It can be used alone or with other treatments, such as chemotherapy (see pages 28–31). Talk to your doctor about your treatment schedule.

Side effects of monoclonal antibody therapy
The most common side effects of monoclonal antibody therapy are flu-like symptoms, such as fever and nausea. These side effects can occur while you are having the treatment or several hours afterwards.

Radiotherapy
Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply. It is generally used for stage I or stage II non-Hodgkin lymphoma when there are cancer cells in one or two areas of lymph nodes in the body. If the cancer is more advanced or aggressive, it may be treated with a combination of radiotherapy and chemotherapy (chemoradiation or chemoradiotherapy).
Karen’s story

I’d been having check-ups with my GP every six months for a few years due to some ongoing health issues. One year, I let too much time pass between appointments, even though I’d been feeling unwell – eating made me feel nauseous and I couldn’t stand to have anything tight around my stomach.

When I did see my GP, I told him about how I’d been feeling and he gave me a physical examination. He booked me in for an ultrasound and a CT scan, which showed an abnormality. I was referred to an oncologist and I had a liver biopsy and another CT scan. The results suggested that I had lymphoma, and a haematologist sent me for another biopsy under general anaesthetic. After that, the diagnosis of non-Hodgkin lymphoma was confirmed.

Over the next few weeks, I had more tests and was told the cancer had spread to my liver, spleen and thyroid. My doctor prescribed chemotherapy once a fortnight for four months.

I received the standard chemotherapy drugs for the first few months of treatment, and I took part in a clinical trial for the last four sessions. The doctor was very pleased with how well the new drugs worked.

During the week I had treatment, I would feel okay as the nurses would give me medicine. The next week, I would get side effects like diarrhoea, vomiting and constipation. I took ginger to help with the nausea, and I tried to live my normal life whenever I felt well enough.

I had such good support from work, my family and friends, and the hospital staff were brilliant. I still have regular check-ups and I’m back to living my usual active life.
Radiotherapy is usually given Monday to Friday for 6–8 weeks. Each session lasts for only a few minutes, but it can take longer to wait for your appointment and set up the equipment. The overall course of treatment will depend on the type of non-Hodgkin lymphoma and your general health. The radiation oncologist will discuss your treatment schedule with you.

During treatment, you will lie alone in a room under a large machine that delivers x-ray beams to the area being treated. You will be able to talk to the radiation therapist through an intercom. Radiotherapy is painless, and you should not feel any discomfort during the sessions.

**Side effects of radiotherapy**
Radiotherapy often causes side effects, such as tiredness and loss of appetite. It can also cause skin irritation and hair loss at the treatment area. These side effects can build up during the course of the treatment, but most will be temporary.

Other side effects depend on the part of the body being treated. For example, radiotherapy to the abdomen may cause an upset stomach, nausea, diarrhoea and infertility; while radiotherapy to the neck can make your mouth and throat sore and dry, cause difficulty swallowing and affect your sense of taste.

For more details about the side effects you may experience, talk to your doctor, call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*, or download a digital version from cancercouncil.com.au.
**Steroid therapy**
Steroids are hormonal substances made naturally in the body. They can also be produced artificially and used as drugs. The steroids that are prescribed to treat non-Hodgkin lymphoma are called corticosteroids.

Steroid therapy is often given with chemotherapy to make chemotherapy more effective. Corticosteroids are usually taken in tablet form, but they can also be given intravenously.

**Side effects of steroid therapy**
Steroid therapy can cause various side effects, which depend on the dose prescribed and the duration of treatment. Most side effects will be temporary and will gradually disappear after you stop taking the medicine.

If you take corticosteroids for a short period of time, side effects may include:
- an increased appetite
- feelings of restlessness
- insomnia
- weight gain
- mood changes.

If you are prescribed steroid therapy for several months, you may experience fluid retention (a build-up of fluid in the body), high blood pressure and high blood glucose levels. You could also develop diabetes. You may be more likely to get infections and, over time, your skin, muscles and bones may weaken.
Speak to your doctor if you feel there are significant changes in your mood while you are taking corticosteroids. The doctor may adjust your dose or recommend you see a psychologist or psychiatrist for ways to help you cope with mood changes.

Your medical team can help you manage or reduce side effects, especially if these effects are causing you discomfort.

**Peripheral blood stem cell transplant**

A peripheral blood stem cell transplant or stem cell transplant may be an option if non-Hodgkin lymphoma returns (recurs or relapses) or does not respond to initial treatment.

Stem cells are immature cells from which blood cells develop. Most stem cells are found in the bone marrow, but a small number are also found in the blood – these are called peripheral blood stem cells. Medicine can also be given to increase the amount of stem cells in the blood (see *Collecting stem cells*, opposite).

There are two main types of stem cell transplants:

**Autologous transplant** – the most common type of transplant recommended to treat non-Hodgkin lymphoma. Your own stem cells will be extracted from your body and frozen, then injected back into your body after high-dose chemotherapy.

**Allogeneic transplant** – less commonly used as a treatment for non-Hodgkin lymphoma. Stem cells are collected from
another person (donor) and injected into your body after high-dose chemotherapy and/or radiotherapy.

The general process for an autologous transplant is described below, but procedures vary from person to person. Talk to your health care team about what to expect, including how long you will have to stay in hospital.

For more detailed information about stem cell transplants, contact the Leukaemia Foundation on 1800 620 420 or leukaemia.org.au.

Collecting stem cells (stem cell harvest)
In the days before a stem cell harvest, you will be given injections of granulocyte-colony stimulating factor (G-CSF). This is a protein used to help the stem cells in the bone marrow multiply as quickly as possible. When the bone marrow is full of stem cells, excess stem cells will spill into the blood.

Once there are enough stem cells in your blood, they will be collected in a cell-separating machine. This process is called apheresis. The machine separates the blood cells into different...
parts – the white blood cell layer containing the stem cells is collected, while the remaining blood cells are returned to your body. A needle will be inserted into each arm – one needle will draw the blood out of your body and into the machine for separation, and the other needle will return the remaining blood cells to your body.

Apheresis is a continuous process and can take several hours. When enough stem cells have been collected, they will be frozen and stored until the transplant.

**Having high-dose chemotherapy and transplanting the stem cells**

Before the transplant, you will have high-dose chemotherapy to kill any remaining cancer cells. The chemotherapy will also destroy your own stem cells in the bone marrow, which can cause side effects (see opposite). You may receive another injection of G-CSF to help the white blood cells to recover more quickly.

A day or so after high-dose chemotherapy, your stem cells will be thawed and returned to you intravenously. These healthy stem cells will travel via your bloodstream and into your bone marrow to restore the stem cells that were destroyed by the chemotherapy.

For some people, stem cells will be collected directly from the bone marrow by suction (aspiration) under general anaesthetic. This is called a bone marrow harvest.
Side effects of high-dose chemotherapy and stem cell transplant

After the chemotherapy and transplant, you will have a low blood count. This will lower your immunity and make you more likely to get infections. To help prevent infection, you will be placed in a room on your own in hospital. You will still be able to have visitors, but they will be restricted.

Other side effects include:
• fatigue
• nausea and vomiting
• diarrhoea
• mouth ulcers
• hair loss
• poor appetite.

Your doctor or transplant nurse will talk to you about possible side effects and ways to manage them.

Recovering from a transplant

After the transplant, you will be in hospital for 1–4 weeks. The length of your stay will depend on whether you have any other health problems and the side effects you experience.

While visitors will be limited, you will be able to do things for yourself, such as shower and go to the toilet, and you can help pass the time with activities like listening to music, reading and watching television. To help with your recovery, your health care team will encourage you to keep yourself occupied and as mobile as possible.
**Going home and follow-up care**

You will be able to leave hospital when your blood counts and general health have improved. You will need regular follow-up care to check your progress and how well the treatment has worked. Your immunity will still be low, so you may have to take regular medicine to reduce the risk of infection. It is not uncommon to become unwell after a transplant and have to go back into hospital.

The time it takes to fully recover from a transplant varies. Talk to your health care team about what to expect while you recover. You can also call Cancer Council 13 11 20 for support.

**Palliative treatment**

Palliative treatment aims to reduce symptoms without trying to cure the disease. It can be used at any stage of advanced cancer to improve quality of life. It is not just for people who are about to die and does not mean you have given up hope. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and other symptoms. Treatment may include radiotherapy, chemotherapy, targeted therapies or other medicine.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. For more information, call Cancer Council 13 11 20 and ask for our booklet on palliative care, or download it from cancercouncil.com.au.
Key points

• Your doctor will recommend treatment based on the type of non-Hodgkin lymphoma you have, the stage, your age and general health, and your preferences.

• Low-grade non-Hodgkin lymphoma grows very slowly and causes few symptoms. Some people with this type of cancer do not have treatment right away, but have regular check-ups instead. This is called watchful waiting.

• High-grade non-Hodgkin lymphoma grows quickly and needs immediate treatment.

• The main treatment for high-grade non-Hodgkin lymphoma is chemotherapy. The aim of treatment is to stop the active cancer and cause remission.

• Chemotherapy can be given in tablet form or via injection into a vein (intravenously).

Treatment will be given as short sessions over several months, with rest periods of a few weeks between each session.

• Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply. It is given Monday to Friday for 6–8 weeks.

• Monoclonal antibody therapy and steroid therapy are often combined with other treatments, such as chemotherapy.

• A peripheral blood stem cell transplant may be an option if the cancer returns or does not respond to initial treatment. You will be in hospital for 1–4 weeks and recovery will take time.

• Palliative treatment may be given to relieve the symptoms of advanced non-Hodgkin lymphoma.
Looking after yourself

Cancer can cause physical and emotional strain. It’s important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet, or download a digital version from cancercouncil.com.au

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel and your doctor’s advice. Cancer Council’s *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or download it from cancercouncil.com.au.
**Relationships with others**

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what’s happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

**Sexuality, intimacy and fertility**

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment is likely to affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call 13 11 20 for free copies of *Sexuality, Intimacy and Cancer, Emotions and Cancer* and *Fertility and Cancer*, or download them from cancercouncil.com.au.
Life after treatment

For most people, the cancer experience doesn’t end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to ‘normal life’, but they don’t want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning, or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, specialist or nurse, as counselling or medicine – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible.

The organisation beyondblue has information about coping with depression and anxiety. Go to beyondblue.org.au, or call 1300 22 4636 to order a fact sheet.
Follow-up appointments
After your treatment, you will need regular check-ups to confirm that the cancer hasn’t come back. Your follow-up schedule will depend on the type of non-Hodgkin lymphoma you were diagnosed with and the treatment you had. Check-ups will become less frequent if you have no further problems.

During these check-ups, you will have a physical examination, blood tests and, possibly, scans.

Between follow-up appointments, let your doctor know immediately of any health problems or new symptoms.

What if non-Hodgkin lymphoma returns?
For some people, non-Hodgkin lymphoma does come back after treatment. This is known as a recurrence or relapse.

Non-Hodgkin lymphoma that has recurred can be treated, with the aim of causing remission or relieving symptoms. Treatment includes chemotherapy and, sometimes, radiotherapy.

If the cancer is more advanced or aggressive, a stem cell transplant combined with high-dose chemotherapy may be recommended (see pages 36–40).
Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council NSW offers free legal and financial services for people who can’t afford to pay – call 13 11 20 to ask if you are eligible.

Talk to someone who’s been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.
In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in a support setting because they aren't trying to protect their loved ones.

**Types of support**

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

"The whole time I was having chemotherapy and radiotherapy, my friend called me every day between 8am and 9am. She could hear if I was well by my voice. There aren’t many friends like that around."  
— Meg
You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out, and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers NSW. Phone 1800 242 636 or visit carersnsw.org.au for more information and resources.

Call Cancer Council 13 11 20 to find out more about carers’ services and to get a copy of the Caring for Someone with Cancer booklet, or download it from cancercouncil.com.au.

“My wife was the unsung hero in all of my treatments, especially when I was so ill during my transplant. All the attention is given to the patient, and often the partner or carer suffers in silence. Who cares for the carer?” George
Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

**Australian**

Cancer Council NSW ........................................ cancercouncil.com.au
Cancer Council Australia ........................................ cancer.org.au
Cancer Australia .................................................. canceraustralia.gov.au
Cancer Connections ............................................. cancercollections.com.au
Carers NSW ....................................................... carersnsw.org.au
Department of Health .......................................... health.gov.au
healthdirect Australia .......................................... healthdirect.gov.au
beyondblue ....................................................... beyondblue.org.au
Australasian Leukaemia & Lymphoma Group ........... allg.org.au
Leukaemia Foundation .......................................... leukaemia.org.au
Lymphoma Australia ............................................ lymphoma.org.au
Talk Blood Cancer discussion forum ..................... talkbloodcancer.com

**International**

American Cancer Society ...................................... cancer.org
Cancer Research UK .............................................. cancerresearchuk.org
Macmillan Cancer Support ..................................... macmillan.org.uk
Leukemia & Lymphoma Society ............................... ilks.org
Lymphoma Research Foundation .............................. lymphoma.org
Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don’t understand, ask for clarification.

- What type of non-Hodgkin lymphoma do I have?
- Has the cancer spread?
- What stage is the cancer?
- What treatment do you recommend and why?
- Are there other treatment choices for me?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost?
- Will the treatment cause any pain? How will the pain be managed?
- Will the treatment affect my sex life or fertility?
- Are the latest tests and treatments for non-Hodgkin lymphoma available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my follow-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the non-Hodgkin lymphoma comes back, how will I know?
- What are my treatment options if the non-Hodgkin lymphoma comes back?
abdomen
The part of the body between the chest and hips that contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

advanced cancer
Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

allogeneic transplant
When stem cells or tissues are taken from one person (donor) and given to another.

alternative therapies
Therapies that are used in place of conventional treatment, often in the hope that they will provide a cure.

anaemia
A reduction in the number or quality of red blood cells in the body.

anaesthetic
A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a person to lose consciousness for a period of time.

angiogenesis
The formation of new blood vessels. It enables tumours to develop their own blood supply, which helps them survive and grow.

antibody
Part of the body’s immune system. Antibodies are proteins made by the blood in response to an invader (antigen) in the body. They help protect against viruses, bacteria and other foreign substances.

apheresis
The process of separating different types of blood cells using a machine.

autologous transplant
When stem cells are taken from a person and reinfused back into their own body.

B-cell
A lymphocyte that forms and matures in the bone marrow.

benign
Not cancerous or malignant.

biological therapies
A range of medicines made from purified versions of chemicals that are made naturally in the body. They include monoclonal antibody therapy. Also called biotherapies.

biopsy
The removal of a sample of cells or tissue from the body for examination under a microscope to help diagnose a disease.

blood count
A test that counts the number of red blood cells, white blood cells and platelets in the blood.

bone marrow biopsy
The removal of a small amount of bone marrow with a needle for examination under a microscope.

cells
The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.
**central nervous system**
The brain and spinal cord.

**chemoradiation**
Treatment that combines chemotherapy with radiotherapy. Also called chemoradiotherapy.

**chemotherapy**
The use of drugs to treat cancer by killing cancer cells or slowing their growth.

**complementary therapies**
Treatments that are used in conjunction with conventional treatment. They might improve general health, wellbeing and quality of life, and help people cope with side effects of conventional cancer treatment.

**CT scan**
A computerised tomography scan. This scan uses x-rays to create a picture of the inside of the body.

**cutaneous T-cell lymphoma**
A type of lymphoma that affects the skin.

**depression**
Very low mood and loss of interest in life lasting for more than two weeks.

**diaphragm**
A dome-like sheet of muscle that divides the chest cavity from the abdomen and is used in breathing.

**diffuse large B-cell lymphoma**
A fast-growing type of lymphoma that starts in lymph nodes in the neck, armpit or groin.

**echocardiogram**
An ultrasound scan of the heart to check its function. Also called a cardiac echo or cardiac ultrasound.

**excision biopsy**
A type of biopsy where a lump is surgically removed (excised) so it can be examined under a microscope.

**fertility**
The ability to conceive a child.

**follicular lymphoma**
A slow-growing type of lymphoma that affects B-cells. The cancer cells grow in circular groups called follicles.

**gated heart pool scan**
A test that shows how the heart is working and how much blood is pumped through the heart.

**granulocyte-colony stimulating factor (G-CSF)**
A protein used to stimulate the growth of stem cells before collection, or to increase the number of white blood cells. G-CSF is given as an injection under the skin (subcutaneously).

**high-grade non-Hodgkin lymphoma**
A fast-growing cancer that starts in the cells of the lymphatic system.

**HIV**
Human immunodeficiency virus, the virus that causes AIDS.

**hormones**
Chemicals in the body that send information between cells to bring about changes in the body.

**immune cells**
White blood cells.
immune system
A network of cells and organs that defends the body against bacteria and viruses.

insomnia
Inability to get to or stay asleep for a prolonged period of time.

intrathecal chemotherapy
Chemotherapy drugs that are delivered via a lumbar puncture.

intravenous (IV)
Injected into a vein.

liver
A large organ in the top right side of the abdomen. The liver plays an important role in metabolism, digestion, detoxification and removal of substances from the body.

low-grade non-Hodgkin lymphoma
A slow-growing cancer that starts in the cells of the lymphatic system.

lumbar puncture
A test in which a needle is inserted into the base of the spine to collect fluid for testing or to inject drugs for treatment. Also called a spinal tap.

lung
One of two spongy organs in the chest cavity made up of large numbers of tiny air sacs. The lungs are used for breathing (respiration).

lymph
A clear fluid that circulates around the body through the lymphatic system. It carries cells that fight infection.

lymphatic system
A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells. Includes the bone marrow, spleen, lymph nodes and thymus.

lymph nodes
Small, bean-shaped glands that form part of the lymphatic system. They collect and destroy bacteria and viruses. Also called lymph glands.

lymphocyte
A type of white blood cell that helps fight infection.

lymphoma
A type of cancer affecting the lymphatic system. There are two main types of lymphoma: non-Hodgkin lymphoma and Hodgkin lymphoma.

lymph vessels
Thin tubes that carry the body’s tissue fluid (lymph) all over the body.

malignant
Cancer. Malignant cells can spread (metastasise) and eventually cause death if they can’t be treated.

mantle cell lymphoma
A type of lymphoma that develops in the outer edge (mantle zone) of B-cells.

monoclonal antibody therapy
Medicine made from different types of proteins that target diseased cells, attach to them and help destroy them.

MRI scan
A magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.
**outpatient**
A person who receives medical treatment without being admitted to hospital.

**palliative treatment**
Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer.

**pathologist**
A specialist doctor who interprets the results of tests (such as blood tests and biopsies).

**peripheral blood stem cell transplant**
The replacement of stem cells in the bone marrow after high-dose chemotherapy with healthy stem cells that have been collected from the blood of the patient or a donor.

**peripheral T-cell lymphoma**
A type of lymphoma that often starts as painless lymph nodes in the neck, armpit or groin.

**PET scan**
A positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution. Cancerous areas show up brighter in the scan because they take up more of the glucose.

**platelets**
One of three types of cells found in the blood. These help the blood to clot and stop bleeding.

**precursor T-lymphoblastic lymphoma**
A type of lymphoma that starts in immature (precursor) T-cells in lymph nodes and the spleen.

**primary cancer**
The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

**prognosis**
The predicted outcome of a person’s disease.

**radiotherapy**
The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

**recurrence**
The return of a disease after a period of improvement (remission).

**red blood cells**
One of three types of cells found in the blood. They carry oxygen around the body.

**relapse**
See recurrence.

**remission**
When the symptoms and signs of cancer reduce or disappear. A partial remission is when there has been a significant reduction in symptoms but some cancer is still present. A complete remission is when there is no evidence of active cancer. This does not necessarily mean the cancer is cured.

**small lymphocytic lymphoma**
A slow-growing lymphoma that is similar to chronic lymphocytic leukaemia.
**staging**
Performing tests to determine how far a cancer has spread.

**stem cells**
Early-stage (immature) blood cells from which red blood cells, white blood cells and platelets develop.

**steroid therapy**
Treatment with drugs to reduce swelling, pain and other symptoms of inflammation.

**T-cell**
A lymphocyte that is produced in the bone marrow and matures in the thymus gland.

**tissue**
A collection of cells that makes up part of the body.

**tumour**
A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

**watchful waiting**
When a person does not need immediate treatment, but instead has their health monitored regularly, with the option of future treatment if necessary.

**white blood cells**
One of three types of cells found in the blood. They help fight infection.

**References**
At Cancer Council, we’re dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia’s Biggest Morning Tea, Relay For Life, Girls’ Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call Cancer Council 13 11 20.
Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn’t just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout NSW (except from mobiles).

If you need information in a language other than English, an interpreting service is available. Call 13 14 50.
If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service. www.relayservice.gov.au
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