



Understanding Non-Hodgkin Lymphoma

A guide for people with cancer,
their families and friends

Cancer
information

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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.



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About this booklet

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 non-Hodgkin lymphoma 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, this information may answer some of your questions and help you think about what to ask your treatment team (see page 56 for a question checklist).

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 (see page 57). You may also like to pass this booklet to 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. You can also visit our website at cancercouncil.com.au.



**Cancer
Council
13 11 20**

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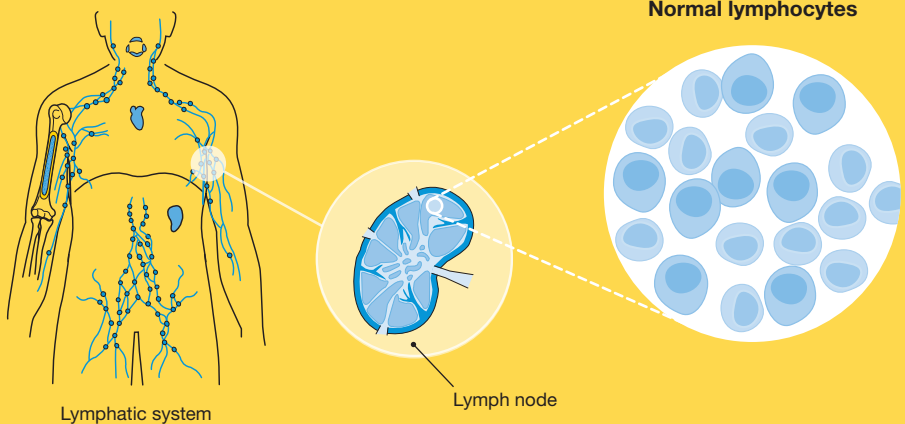
What is blood cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Cancer develops when cells become abnormal and keep growing. When a cancer begins in abnormal blood cells, it is known as a blood cancer.

The three main groups of blood cancers are lymphoma, leukaemia and myeloma. Lymphoma is cancer of the body's lymphatic system (see pages 6–7). In lymphoma, abnormal white blood cells called lymphocytes grow and multiply uncontrollably and can form a lump

How lymphoma starts

Lymphoma usually begins in a lymph node.

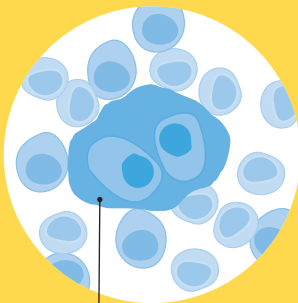


(tumour), usually in a lymph node. If these abnormal lymphocytes continue to build up, they can spread through the lymph vessels to form a tumour in another part of the lymphatic system. Occasionally, lymphoma travels through the bloodstream to form a tumour in an organ outside the lymphatic system, such as the liver or lung.

As the abnormal lymphocytes replace normal cells, the body's immune system often becomes less able to fight infections.

Sometimes other types of cancer spread to the lymph nodes. This is not lymphoma. For example, breast cancer that has spread to the lymph nodes is still called breast cancer.

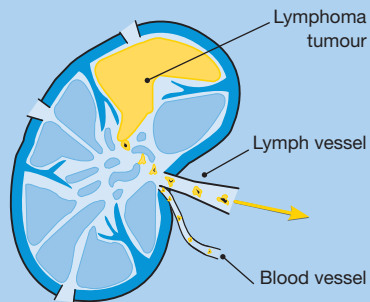
→ **Abnormal lymphocytes**



Abnormal lymphocytes multiply and form a tumour

How lymphoma spreads

Lymphoma can travel through the lymphatic system (or sometimes through the blood) to other parts of the body.





The lymphatic system

Non-Hodgkin lymphoma is a cancer of the lymphatic system. The lymphatic system is part of the immune system, which protects the body against disease and infection. The lymphatic system is made up of a network of vessels, tissues and organs:

Lymph vessels – These thin tubes are found throughout the body and in organs such as the spleen, liver, thymus gland and bone marrow. Lymph vessels carry lymph fluid around the body.

Lymph fluid – This clear fluid travels to and from the tissues in the body, carrying nutrients and taking away bacteria, viruses, abnormal cells and cell debris.

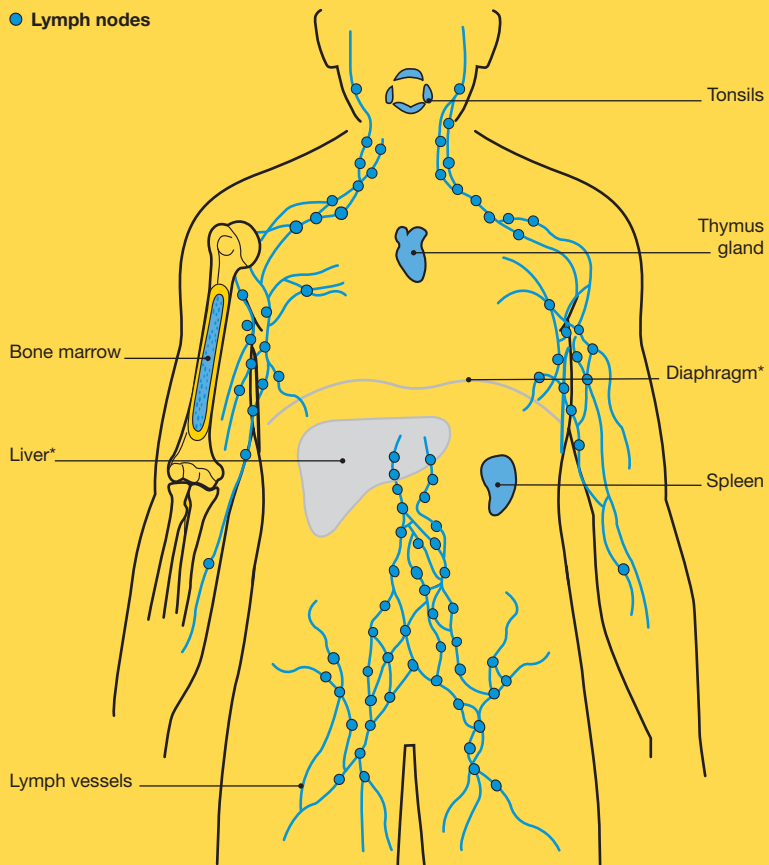
Lymph nodes – Also called lymph glands, these small, bean-shaped structures are made up of lymph tissue. There are about 600 lymph nodes found in groups along the lymph vessels, including in the neck, underarms, chest, abdomen and groin. The lymph nodes filter lymph fluid as it passes through the body, before emptying most of the fluid into the bloodstream.

Other lymph tissue – As well as lymph nodes, lymph tissue is found in other parts of the body:

- bone marrow – produces blood cells (see page 8)
- thymus gland – helps produce white blood cells
- spleen – stores white blood cells, filters waste products from the blood, and destroys old blood cells, abnormal cells and bacteria
- tonsils – trap inhaled or ingested germs
- digestive system – stores immune cells.

Anatomy of the lymphatic system

● Lymph nodes



* Not part of the lymphatic system

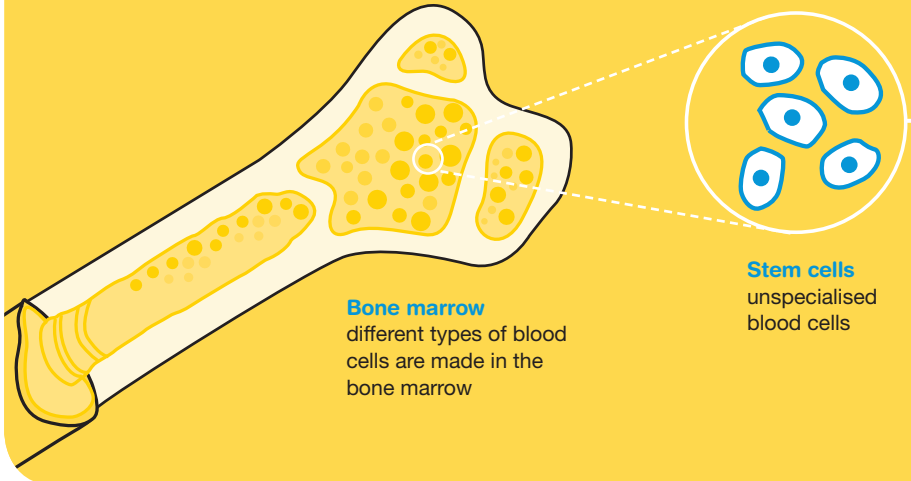
The role of blood cells

The bone marrow is the soft, spongy material inside bones. It produces stem cells, which are unspecialised blood cells that usually grow into one of three main types of blood cells: red blood cells, white blood cells and platelets. Each type of blood cell has a specific function (see below).

There are different types of white blood cells. The lymph nodes, lymph tissue and lymph fluid all contain the white blood cells known as lymphocytes.

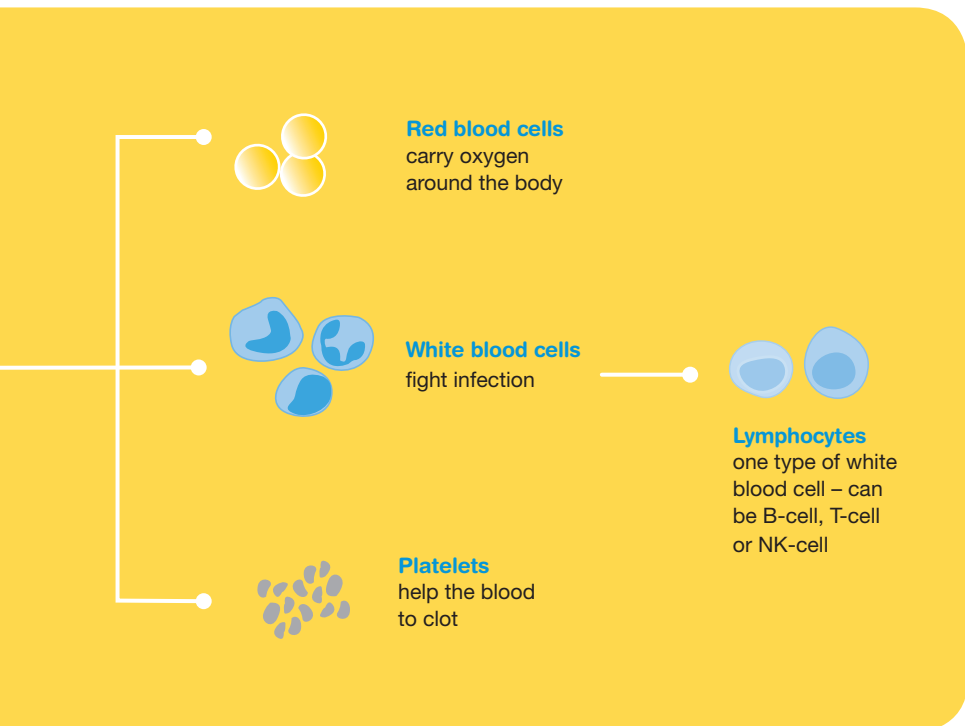
Types of blood cells

The blood contains different types of cells, which all play different roles. Lymphoma begins when white blood cells known as lymphocytes become abnormal.



Types of lymphocytes are B-cells, T-cells and NK-cells. B-cells make antibodies to fight infection. T-cells help the body fight invaders (antigens) by killing them directly or by helping B-cells make antibodies. NK-cells are rarer lymphocytes that specialise in killing cancer cells.

For more information about all types of blood cancers and the role of blood cells, visit the Leukaemia Foundation at leukaemia.org.au/disease-information.





Key questions

Q: What is non-Hodgkin lymphoma?

A: Non-Hodgkin lymphoma is a blood cancer that begins in the white blood cells called lymphocytes (see pages 8–9). It is sometimes called non-Hodgkin's disease. It is one of the two main groups of lymphoma. The other group is Hodgkin lymphoma (see box below).

Most commonly, non-Hodgkin lymphoma starts in a lymph node at one or more places in the body. It can spread through the lymphatic system from one group of lymph nodes to another. It can also spread to other lymph tissue, particularly in the bone marrow and spleen, or to lymph nodes in the liver.

Sometimes non-Hodgkin lymphoma starts in or spreads to tissue in an organ outside the lymphatic system, such as the stomach, bone, skin, brain and spinal cord (central nervous system). This is known as extranodal disease.

Different types of lymphoma

There are two main types of lymphoma: non-Hodgkin and Hodgkin. Non-Hodgkin lymphoma is more common. The two types look different when the diseased cells are examined under a microscope. A type of lymphocyte called a Reed-Sternberg cell is usually found in Hodgkin lymphoma, but not in non-Hodgkin lymphoma. This booklet is only about non-Hodgkin lymphoma.

▶ See our *Understanding Hodgkin Lymphoma* booklet.

Common types of non-Hodgkin lymphoma

There are many different types of non-Hodgkin lymphoma, based on the type of lymphocyte affected (B-cell, T-cell or rarely NK-cell) and how fast the lymphoma is growing (see pages 22–23).

B-cell lymphomas (around 85% of cases)

diffuse large B-cell	the most common type of non-Hodgkin lymphoma in Australia; fast-growing; an intermediate-grade lymphoma
follicular	cells grow slowly in lymph nodes in circular groups called follicles; may be low- or intermediate-grade
small lymphocytic	a slow-growing cancer that is similar to chronic lymphocytic leukaemia; a low-grade lymphoma
mantle cell	develops in the outer edge (mantle zone) of lymph nodes; can look like a low-grade lymphoma, but can act like a high-grade lymphoma

T-cell lymphomas (around 15% of cases)

precursor T-lymphoblastic	starts in immature (precursor) T-cells in the lymph nodes and the spleen; a high-grade lymphoma
peripheral T-cell	often occurs as widespread enlarged, painless lymph nodes; an intermediate or high-grade lymphoma
cutaneous (skin) T-cell	primarily affects the skin and starts as red, scaly patches or raised bumps that can be itchy; a low-grade lymphoma

Q: What are the risk factors?

A: The causes of non-Hodgkin lymphoma are largely unknown, but the risk factors include:

Weakened immune system – The risk is higher if your immune system has been weakened. This can happen if you have an autoimmune disease, such as rheumatoid arthritis and coeliac disease, or if you need to take medicines that suppress the immune system after an organ transplant.

Certain viruses – Infections with *Helicobacter pylori*, HTLV-1 (human T-cell lymphotropic virus 1), hepatitis C, Epstein-Barr virus and human herpesvirus 8 can slightly increase the risk of non-Hodgkin lymphoma.

Family history – Having a parent, brother or sister who has had non-Hodgkin lymphoma slightly increases a person's risk of developing it. However, this family link is rare.

Most 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.



For an overview of what to expect during all stages of your care for non-Hodgkin lymphoma, visit cancerpathways.org.au/optimal-care-pathways/lymphoma. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Q: How common is it?

A: Each year in Australia, about 5000 people are diagnosed with non-Hodgkin lymphoma.² It is more common in men than women. Most cases occur in adults aged 60 and older. However, non-Hodgkin lymphoma 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 found in the body. The most common symptom is a painless swelling of a lymph node (e.g. in the neck, underarm or groin).

Non-hodgkin lymphoma can cause what are known as “B symptoms”:

- unexplained and regular fevers
- excessive sweating, particularly at night
- loss of appetite or unintentional weight loss.

Other symptoms may include ongoing tiredness (known as fatigue) or itchy skin (rarely). Sometimes non-Hodgkin lymphoma starts in lymph nodes in deeper parts of the body, such as the stomach (causing bloating) or the chest (causing coughing and difficulty breathing).

These symptoms 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).

Q: Which health professionals will I see?

A: Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, such as a haematologist or medical oncologist. The specialist will arrange further tests to work out if you have non-Hodgkin lymphoma.

Health professionals you may see

haematologist*	diagnoses and treats diseases of the blood, bone marrow and lymphatic system; prescribes chemotherapy and other drug therapies; conducts stem cell transplants
medical oncologist*	treats cancer with chemotherapy and other drug therapies; in some cases, may be the main treating specialist instead of a haematologist
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
radiation therapist	plans and delivers radiation therapy
cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
haematology nurse	administers chemotherapy and other drugs, and provides care, information and support throughout treatment

If non-Hodgkin lymphoma is diagnosed, the specialist will consider your treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different areas of your care.

dietitian	recommends an eating plan to follow while you are in treatment and recovery
pharmacist	dispenses medicines and gives advice about dosage and side effects
social worker	links you to support services and helps you with emotional, practical and financial issues
counsellor, psychologist	help you manage your emotional response to diagnosis and treatment
physiotherapist, occupational therapist	assist with physical or practical problems, including restoring movement and mobility, and recommending aids and equipment
palliative care specialists* and nurses	work closely with the GP and cancer team to help control symptoms and maintain quality of life

**Specialist doctor*



Diagnosis

If your GP suspects that you have non-Hodgkin lymphoma, they will feel the lymph nodes in your neck, underarms and groin for swelling. They will also feel your throat, tonsils, neck, chest and abdomen for swelling. Your GP may organise further tests or refer you to a specialist.

Biopsy

Removing some cells and tissue from an enlarged lymph node is the only way to confirm a diagnosis of non-Hodgkin lymphoma. This is called a biopsy and it is done in one of two ways (see table below).

Excision biopsy

- The whole lymph node or part of it is removed with surgery. This may be done as day surgery or you may be in hospital for a few days.
- Depending on the node's location, you'll have a local or general anaesthetic.
- The wound will usually be closed with stitches. These will be removed about a week later.
- This is the preferred type of biopsy for non-Hodgkin lymphoma because it helps ensure an accurate diagnosis and staging of any lymphoma found.

Core biopsy

- A hollow needle is inserted into the lymph node to remove some cells and a small piece of tissue. It can be done as day surgery with a local anaesthetic.
- Ultrasound or CT scan may be used to guide the needle to the correct node.
- Core biopsy is usually done when it is difficult to remove the lymph node or when non-Hodgkin lymphoma has returned after treatment.
- Depending on the pathology results, you may need to have an excision biopsy.

After the biopsy

The biopsy sample is sent to a laboratory for examination under a microscope by a specialist doctor called a pathologist. If cancer cells are found, the pathologist can tell which type of non-Hodgkin lymphoma they are.

The results will usually be ready in 7–10 days. This waiting period can be an anxious time and it may help to talk to a supportive friend, relative or health professional about how you are feeling.

Further tests

Sometimes further tests are needed to find out whether the cancer has spread. This is called staging (see pages 22–23).

The following pages describe tests that are commonly used to help stage non-Hodgkin lymphoma. You will probably not need to have all these tests – most people will have blood tests (see below) and some imaging tests (see pages 19–21). Some tests may be repeated during or after treatment to check your health and how well the treatment is working.

Blood tests

Your doctor will take a blood sample to see how well your kidneys and liver are working, and to check your general health. Low blood counts before treatment may indicate that the cancer has spread to the bone marrow. You will also have regular blood tests to check the effects of treatment on your total number of red blood cells, white blood cells and platelets (see pages 8–9).

“ My diagnosis was made after the biopsy. I felt relieved to finally have a label for my illness. ” Joel

Bone marrow biopsy

You may have a biopsy to check whether non-Hodgkin lymphoma has spread to the bone marrow. A bone marrow biopsy is done in two steps:

Bone marrow aspiration – The doctor inserts a needle into the bone at the back of your hip (pelvic bone) to remove a small sample of fluid (aspirate) from the bone marrow.

Bone marrow trephine – A second needle is used to take a matchstick-wide sample of both bone and bone marrow tissue.

A bone marrow biopsy takes about 30 minutes. It is usually done as an outpatient procedure and you do not need to stay in hospital overnight. You will lie still while a local anaesthetic is injected into your pelvis (hip) to numb the area. You may also be offered light sedation to help you feel relaxed, or a general anaesthetic.

You may feel some pressure or discomfort during the biopsy. If you feel uncomfortable afterwards, ask a member of your health care team about pain-relieving medicine. You will need to lie flat in bed for another 30 minutes after the biopsy to make sure there is no bleeding.

The bone marrow sample is examined under a microscope to see if any lymphoma cells are present. Results are usually available within a couple of days to a week.

Imaging tests


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

Chest x-ray – Before an excision biopsy, you may have an x-ray of the chest area to see if the lymphoma has spread to the lymph nodes in your chest or lungs. An x-ray is painless and takes only a few minutes.

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

Before the scan, you may be asked to drink a liquid or have a special dye called contrast injected into a vein. This helps ensure that anything unusual can be seen more clearly. The dye 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, and takes 30–45 minutes. Most people can go home as soon as the scan is over.



Before having scans, tell the doctor if you have any allergies or have had a reaction during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant.

PET-CT scan – This specialised test combines a positron emission tomography (PET) scan with a non-contrast CT scan to produce a three-dimensional colour image.

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

You will be asked to sit quietly for 30–90 minutes while the glucose moves around your body, then the PET scan itself will take about 30 minutes. Clinic staff will tell you how to prepare for the scan, particularly if you are diabetic. You'll be encouraged to drink plenty of water to help the glucose solution leave your body.

The CT scan (see previous page) is used to help work out the precise location of any abnormalities revealed by the PET scan.

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 technician called a sonographer will spread gel over your skin and then pass a small device called a transducer 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.

An ultrasound is painless and takes only a few minutes.

MRI scan – MRI (magnetic resonance imaging) scans are not commonly used for people with non-Hodgkin lymphoma, but may be used to check the brain and spinal cord.

The MRI scan uses a combination of a powerful magnet and radio waves to create detailed pictures of areas inside the body. You will lie on a treatment table that slides into a metal cylinder. The test is painless, but some people find lying in the cylinder noisy and confined. An MRI scan takes 30–60 minutes.

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) for lymphoma cells. This is uncommon, so most people with non-Hodgkin lymphoma will not need to have a lumbar puncture. Sometimes a lumbar puncture may also be used to deliver chemotherapy (see page 32).

If you do have a lumbar puncture, you will be placed in a curled or sitting position and given a local anaesthetic. A thin needle will be inserted to remove some fluid from the space between the bones in your lower back. You may feel some discomfort. Tell your doctor if you feel any pain, as they may be able to give you some more anaesthetic.

After the procedure, you may have to lie on your back for a short time to help prevent a headache starting. 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.

Staging and grading

Staging is a way of describing how far non-Hodgkin lymphoma has spread throughout the body. The tests described on pages 16–21 help your doctors determine the stage of the cancer. The table opposite describes the different stages of non-Hodgkin lymphoma. Knowing the stage helps your doctor work out the best treatment for you. Your doctor can explain your stage to you.

As well as a number, each stage is given a letter according to whether you are experiencing specific symptoms:

- “A” means you feel well, with none of the B symptoms of non-Hodgkin lymphoma.
- “B” means you have some or all of these symptoms – unexplained fevers, unexplained weight loss or drenching night sweats.

Doctors also give non-Hodgkin lymphoma a grade, which describes how quickly the lymphoma is likely to grow and spread.

The two grades of non-Hodgkin lymphoma are low-grade and high-grade, and they are treated in slightly different ways. Follicular lymphoma is the most common type of low-grade lymphoma. Diffuse large B-cell lymphoma is a common high-grade lymphoma. The table opposite describes the different grades.

“ I now understand what they mean by ‘information means control’. Seeking accurate, reliable information was a huge coping strategy for me. ” Sonya

Stages of non-Hodgkin lymphoma

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 on the same side of the diaphragm.
stage III	Lymph node areas both above and below the diaphragm are affected.
stage IV	Lymphoma is in multiple lymph nodes and has spread to other parts of the body (e.g. bone marrow, liver, lungs).

Grades of non-Hodgkin lymphoma

low-grade (slow-growing)	Doctors may call this indolent lymphoma. It may cause few symptoms in the beginning because there is little change in the cancer over time. It often doesn't need to be treated straightaway.
intermediate-grade and high-grade (fast-growing)	Doctors may also call this aggressive 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 (see page 25).



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 a specialist and 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 my work, 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.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your haematologist (or medical oncologist if they are your main treating specialist).

However, it is not possible for anyone to predict the exact course of your disease. Instead, your doctor can give you an idea about common issues that affect people with your type of non-Hodgkin lymphoma.

Important factors in assessing your prognosis include:

- your test results
- the type of non-Hodgkin lymphoma you have
- the stage
- the rate and depth of tumour growth
- the likelihood of response to treatment
- other factors such as your age, level of fitness and medical history.

You will also have tests throughout your treatment that show how well the treatment is working.

Most people who are treated for non-Hodgkin lymphoma go into remission after treatment. Remission means the symptoms of cancer have decreased or disappeared and there is no evidence of disease on physical examination or imaging tests. During remission, you will need regular check-ups to ensure that you are still healthy and the cancer hasn't returned.

People may experience multiple episodes (recurrences) of the disease during their lifetime, meaning they go in and out of remission. See page 51 for more information about treatment for recurrence.



Key points about diagnosis

Initial tests

Your GP will do a physical examination to check whether your lymph nodes are swollen.

Diagnostic tests

A biopsy of a swollen lymph node is the most common way to diagnose non-Hodgkin lymphoma. All or part of the lymph node will be removed and the cells will be examined under a microscope.

Other tests

Other tests provide more information to help plan your treatment:

- Blood tests check how well your liver and kidneys are working. You will have regular blood tests to track the effect of treatment.
- You may need a bone marrow biopsy, which involves inserting a needle into the pelvic bone to remove small samples of fluid and bone for examination.
- Imaging tests work out whether non-Hodgkin lymphoma has spread. These may include x-ray, CT or PET-CT scan, ultrasound and MRI scan.
- Some people have a lumbar puncture to see if the lymphoma has spread to the central nervous system.

Prognosis

- Your prognosis will depend on several factors, such as the stage and grade.
- After initial treatment, most people go into remission but many 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, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 15) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 56 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist 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 your first doctor. You might decide you would prefer to be treated by the second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

- See our *Cancer Care and Your Rights* booklet and our “Making Treatment Decisions” podcast episode.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit

australiancancertrials.gov.au.

- See our *Understanding Clinical Trials and Research* booklet.

Treatment

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 reduce or get rid of all signs and symptoms of the lymphoma. This is called remission. Remission may last for a long period of time and most people have a good quality of life. Sometimes non-Hodgkin lymphoma becomes active again and further treatment is required (see page 51).

Treatment will depend on how fast the lymphoma is growing (the grades, see pages 22–23):

Low-grade (slow-growing) lymphoma – may not need treatment straightaway but needs regular check-ups (watchful waiting, see page 31). If a change or growth in the cancer is causing symptoms or other warning signs, your doctor will recommend treatment.

Intermediate-grade and high-grade (fast-growing) lymphoma – needs to be treated quickly.

There are many different treatments for non-Hodgkin lymphoma. If your treatment team has recommended you start treatment, this may include one or more of the following:

- chemotherapy (pages 31–36)
- steroid therapy (pages 37–38)
- targeted therapy (pages 38–39)
- radiation therapy (pages 40–41)
- stem cell transplant (pages 43–45).

What to do before treatment starts

Talk with your doctor about whether you need to do anything to prepare for treatment.

Check heart function

Radiation therapy to the chest and some types of chemotherapy may affect the way your heart works (see page 42). Your doctor may recommend you have some tests before, during and/or after treatment to check your heart function.



Ask about fertility

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. You may be able to store sperm, eggs, ovarian tissue or embryos.

- › See our *Fertility and Cancer* booklet, or download a copy from cancercouncil.com.au.

Get a dental check-up

If possible, see a dentist before having chemotherapy, a stem cell transplant, or radiation therapy to the head and neck area. If mouth and teeth problems are left untreated, they can lead to infections after cancer treatment.

- › See our *Mouth Health and Cancer Treatment* fact sheet.



Watchful waiting

If you are diagnosed with low-grade non-Hodgkin lymphoma (see pages 22–23), you may not have treatment straightaway. Instead you may have regular check-ups to monitor the cancer. This approach is called watchful waiting (or watch and wait).

Having treatment earlier than necessary can cause 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 who have untreated low-grade non-Hodgkin lymphoma continue their usual daily activities for many years. Some people find watchful waiting hard to accept and prefer to have treatment immediately. If waiting for treatment makes you feel anxious, speak with your treatment team. They may be able to put you in touch with someone who has had a similar experience.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells or slow their growth. For low-grade non-Hodgkin lymphoma, chemotherapy is often combined with other treatments. Chemotherapy is the main treatment for aggressive non-Hodgkin lymphoma. It is also sometimes given as palliative treatment (see page 46).

“ I became good friends with a lady who began chemotherapy on the same day as me. We ended up going walking several times a week for 18 months. The companionship was a great support. ” *Tania*

Having chemotherapy

Chemotherapy is most commonly given through a drip into a vein in your arm (intravenously). Intravenous infusions may be given through a specially placed device depending on how often you need chemotherapy, how long it takes to give each dose, and how long the device needs to stay in place. Types of devices include:

PICC (peripherally inserted central catheter) – A thin tube that can stay in place for a long period of time. A PICC is inserted into a vein in the arm.

Port-a-cath (port) – A small device that is surgically inserted under the skin of the chest or arm. A tube called a catheter connects the port to a vein so fluids can be passed into the body.

Central line (central venous catheter or CVC) – A thin tube with several openings that is inserted into a vein in the neck or chest.

Cannula (drip) – A small, hollow plastic tube that is inserted into the hand or arm.

Some chemotherapy drugs for non-Hodgkin lymphoma are given as tablets. Occasionally, chemotherapy is given into the fluid around the spine through a lumbar puncture (see page 21). Having drugs this way is called intrathecal chemotherapy, and it is done to prevent or treat non-Hodgkin lymphoma in the brain or spinal cord.

You'll usually have a combination of drugs spread over 4–6 months. The drug combination and treatment schedule will depend on the

type of non-Hodgkin lymphoma. While each person's schedule varies, generally chemotherapy is given over a few days, followed by a rest period to allow the blood counts to return to normal before the next round of chemotherapy.

Throughout treatment, you will be closely monitored by your doctor and you will have tests to see how well the chemotherapy drugs are working. As chemotherapy can reduce the number of blood cells, you will have regular blood tests to check your blood count, and your liver and kidney function. You may also be given injections of a drug known as granulocyte-colony stimulating factor (G-CSF). This helps increase your white blood cell count and protect you from infection.

Chemotherapy treatment may be repeated several times until tests show that the cancer is in remission.

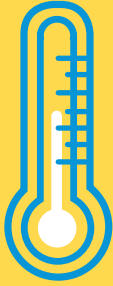
Side effects of chemotherapy

Chemotherapy drugs can damage healthy, fast-growing cells, such as the cells in your hair, mouth and blood. This causes side effects. Some people don't experience any side effects, others have several. Some of the common side effects experienced by people who have chemotherapy for non-Hodgkin lymphoma are described on the following two pages.

During chemotherapy, you may be able to continue to work and carry out your daily activities, but you may need to rest when you feel tired. Let your doctor or nurses know of any side effects you experience. Most side effects are temporary. Your treatment team can help you prevent or manage any side effects.

Common side effects of chemotherapy

Everyone reacts to chemotherapy differently. For more information about chemotherapy and its side effects, call Cancer Council **13 11 20**, or see our *Understanding Chemotherapy* booklet.



Increased risk of infections

Chemotherapy reduces your white blood cell level (neutropenia), making it harder for your body to fight infections. Colds and flu may be easier to catch and harder to shake off, and scratches or cuts may get infected more easily. You may also be more likely to catch a more serious infection. See page 36 for ways to reduce your risk of infection.

Nausea and vomiting

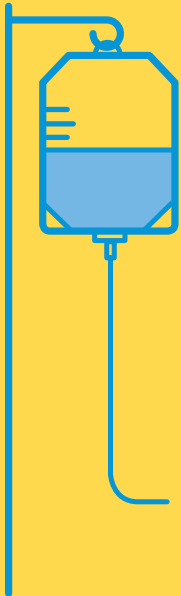
You will usually be given anti-nausea medicines with each chemotherapy session to stop you feeling sick (nauseous) or vomiting. These usually work very well. If you still feel sick or are vomiting after using the prescribed medicine, let your nurse or doctor know so that another medicine can be tried.

- ▶ See our *Nutrition and Cancer* booklet and listen to our “Appetite Loss and Nausea” podcast episode.



Constipation

Some chemotherapy drugs and anti-nausea medicines can cause constipation. Ways to prevent constipation include drinking 6–8 glasses of water a day, eating a high-fibre diet and getting daily exercise. Your treatment team may also suggest or prescribe a suitable laxative or stool softener.



Bleeding or bruising

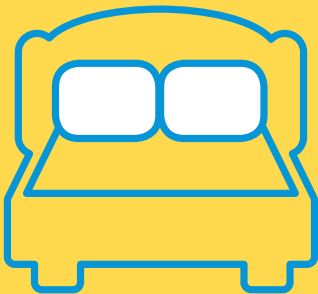
A drop in the number of platelets in your blood (thrombocytopenia) can cause heavy bleeding from small cuts or make you bruise easily. You may be given a platelet transfusion to increase your platelet count.



Hair thinning/hair loss

Your hair will grow back after treatment, but it may look or feel different. The hospital may have a wig library. If you have private health insurance, check with your provider whether you are entitled to a rebate on a wig for hair loss due to chemotherapy.

➤ See our *Hair Loss* fact sheet.



Fatigue

Severe tiredness and lack of energy (fatigue) may make you feel drowsy, exhausted or confused. These feelings can last for several weeks or months after having chemotherapy. Check with your doctor whether your fatigue is related to a low red blood cell count (anaemia). This can be treated by blood transfusions.

➤ See our *Fatigue and Cancer* fact sheet and listen to our “Managing Cancer Fatigue” podcast episode.

Taking care with infections

If your white blood cell levels drop during treatment, you are more likely to catch colds or more serious infections and need to go to hospital.

Reduce your risk

To prevent the spread of infection:

- check with your doctor about having the flu vaccine
- ask people close to you to consider having a flu shot
- ask family or friends with a cold, flu or other contagious infection (e.g. measles, chickenpox or a cold sore) to wait until they are well before visiting
- as far as practical, avoid close contact with the people you live with if they are unwell
- try to avoid crowded places, such as shopping centres or public transport in peak hour
- wash your hands with soap and water before preparing food and eating, and after using the toilet
- prepare and store food properly to avoid foodborne illnesses and food poisoning
- eat freshly cooked foods
- avoid raw fish, seafood, meat, eggs and soft cheeses
- wash fruits and vegetables well before eating.

When to seek medical help

Contact your doctor or go to the nearest hospital emergency department immediately if you experience one or more of the following symptoms:

- a temperature of 38°C or higher
- chills or shivering
- sweating, especially at night
- burning or stinging feeling when urinating
- a severe cough or sore throat
- shortness of breath
- vomiting that lasts more than a few hours
- severe abdominal pain, constipation or diarrhoea
- unusual bruising or bleeding, such as nosebleeds, blood in your urine or black bowel motions
- ongoing faintness or dizziness and a rapid heartbeat
- any tenderness, redness or swelling around the site of the intravenous chemotherapy device
- any sudden decline in your health.

Steroid therapy

Steroids are substances made naturally in the body. They can also be produced artificially and used as an anti-inflammatory drug. The most commonly prescribed steroids for non-Hodgkin lymphoma are called corticosteroids.

Having steroids

You may be given steroids to increase the effect of chemotherapy, help destroy the lymphoma, and treat any nausea or vomiting. Corticosteroids are usually taken in tablet form, but can also be given into a vein (intravenously).

Side effects of steroids

Steroid therapy can cause various side effects, which depend on the dose prescribed and how long you have treatment. Most side effects are temporary and will gradually disappear after you stop taking the medicine.

When taken for a short period of time, steroids may cause an increased appetite, feelings of restlessness, trouble sleeping (insomnia), weight gain and mood changes.

If you need to take steroids for several months, you may experience a build-up of fluid in the body, high blood pressure and high blood glucose levels (which may lead to diabetes in some people). There is an increased risk of developing stomach ulcers, so your doctor should prescribe an anti-ulcerant drug while you are on steroid therapy. You may also be more likely to get infections (see opposite page) 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 treatment team can help you manage or reduce side effects, especially if they are causing you discomfort.

Targeted therapy

Targeted therapy drugs attack specific particles (molecules) in cancer cells to stop the cancer growing or to reduce its size. Some types of non-Hodgkin lymphoma are treated with a group of targeted therapy drugs called monoclonal antibodies. The monoclonal antibody most commonly used for non-Hodgkin lymphoma is rituximab, which can treat many types of B-cell lymphomas. It does not work for T-cell or NK-cell lymphomas. Some B-cell lymphomas that do respond to rituximab may become resistant.

Monoclonal antibodies are manufactured versions of immune system proteins called antibodies, which are part of the body's natural defence against infection. These antibodies target and attach to cancer cells. This makes it easier for the body's immune system to find and destroy these cells.

Having monoclonal antibodies

Monoclonal antibodies are generally given through a drip into a vein or as an injection under the skin. They are usually combined with chemotherapy and are commonly given in repeating cycles. Talk to your doctor about your specific treatment schedule.

Side effects of monoclonal antibodies

Your doctor will discuss any potential side effects with you before you start treatment. Some people may have a reaction (e.g. nausea, skin rashes and itching) during or several hours after having these drugs. You will probably be given medicine to help prevent such a reaction and you will have regular check-ups during treatment. Other side effects can include headache, fatigue, anaemia, flu-like symptoms and an increased risk of abnormal bleeding.

In some people, rituximab can reactivate some viral infections, such as hepatitis B. It can also increase your risk of getting another infection (see page 36). It is important to discuss any side effects with your doctor immediately. If left untreated, some symptoms can become life-threatening.

Small molecule inhibitors

Small molecule inhibitors are another type of targeted therapy. These drugs can get inside cancer cells and block certain enzymes that tell the cancer cells to grow.

Two small molecule inhibitors, ibrutinib and idelalisib are used to treat some types of low-grade lymphoma that have not responded to treatment or have come back.

Talk with your doctor about whether these treatments (or another drug available on a clinical trial) are suitable for your situation.

These drugs have the potential to cause a variety of side effects – your doctor will discuss these with you before treatment.

Radiation therapy

Radiation therapy (also known as radiotherapy) uses radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Your treatment will be carefully planned and precisely targeted to the parts of the body affected by lymphoma. The aim is to do as little harm as possible to your healthy cells.

Radiation therapy for non-Hodgkin lymphoma can be used on its own or after chemotherapy:

- to treat some early-stage, low-grade non-Hodgkin lymphomas
- in certain circumstances in combination with chemotherapy (known as chemoradiation)
- to treat a specific tumour that is growing rapidly, bleeding or causing pain, which sometimes happens after chemotherapy has stopped working
- as part of an allogeneic transplant (see page 43).

Having radiation therapy

Before starting treatment, the radiation therapist may make some small permanent tattoos or temporary marks on your skin so that the same area is targeted during each treatment session.

If you are having radiation therapy to your head or neck region, the radiation therapist may also fit you with a plastic mask called an immobilisation mask. This keeps your head and neck in the exact same position every day, and the marks are put on the shell, not on the skin of your face or neck. If you have issues with claustrophobia, let the radiation therapist know at the planning appointment.

The course of treatment will depend on the type of non-Hodgkin lymphoma and your general health. You will usually have treatment as an outpatient once a day, Monday to Friday, for about 3–4 weeks. Each session takes only a few minutes, but it can take longer to set up the equipment and wait for your appointment. The radiation oncologist will discuss your treatment schedule with you.

During treatment, you will lie alone in a room under a large machine called a linear accelerator that delivers x-ray beams to the area being treated. Imaging scans are taken throughout the treatment course so that the radiation therapy team can monitor your response to treatment. Radiation therapy is painless, and you should not feel any discomfort during the sessions.

Side effects of radiation therapy

The most common side effects of radiation therapy are tiredness, loss of appetite, skin irritation and hair loss at the treatment area. These side effects can build up towards the end of the course of treatment, but most will be temporary. You will have regular reviews with the radiation oncologist or other team members to monitor your progress and support you.

Other side effects will depend on the part of the body being treated. For example, radiation therapy to the abdomen may cause an upset stomach, nausea, diarrhoea and infertility; while radiation therapy to the neck can make your mouth and throat sore and dry, cause difficulty swallowing, and affect your sense of taste. Talk to your treatment team about any side effects that concern you.

➤ See our *Understanding Radiation Therapy* booklet.

Late effects of treatment

Some side effects from treatment may not show up until many months or years later. These are called late effects. Your doctor will talk to you about these before your treatment starts.

Second cancers – Occasionally, many years after successful treatment for non-Hodgkin lymphoma, some people may develop a new, unrelated cancer. This may be either a new form of lymphoma or leukaemia, or a type of solid cancer. Sometimes this happens because of being diagnosed at a young age with lymphoma, being treated with certain chemotherapy drugs, or having a genetic link. In some cases, radiation therapy can also increase the risk of developing a second cancer near the area treated.

Heart problems – Some forms of drug treatments may damage the heart muscle so it doesn't work as well. If this is a concern for you, your doctor will monitor your heart function throughout treatment to limit your risk of developing this condition. They will adjust your chemotherapy if early changes are seen. Radiation therapy to the chest area may also lead to heart disease.

Thyroid problems – Radiation therapy to the neck area may cause an underactive thyroid gland, and you may need daily thyroid pills.



It is important that you talk to your doctor about any symptoms that appear, even many years after treatment. Modern treatment plans are, however, designed to reduce these late effects.

Stem cell transplant

If non-Hodgkin lymphoma returns (recurs) or does not respond to initial treatment, you may need high doses of chemotherapy to help destroy the cancer cells. This can also damage the stem cells, and you may need a stem cell transplant to help restore the bone marrow and rebuild your immune system.

Stem cells are unspecialised blood cells (see page 8). 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.

There are two main types of stem cell transplants.

Autologous transplant – when your stem cells are removed from your blood and later put back (reinfused) into your body. This is the most common type of transplant used to treat non-Hodgkin lymphoma.

Allogeneic transplant – when the stem cells are collected from another person (a donor). This type of transplant is less commonly used to treat non-Hodgkin lymphoma.

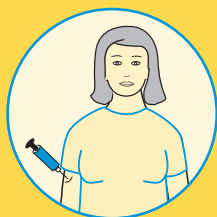
A stem cell transplant is a demanding treatment and is not suitable for everyone, especially people with other health problems. The entire procedure, including recovery, can take months. A transplant is done in several steps, which are described on the next two pages.

For more information, talk to your transplant team, contact the Leukaemia Foundation on 1800 620 420 or visit leukaemia.org.au.

Steps in an autologous stem cell transplant

This is a general outline of a transplant using your own stem cells, but the process varies. Talk to your transplant team about what to expect.

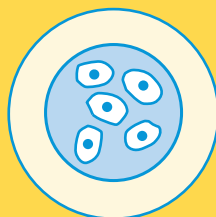
1 Stem cells stimulated



The first step is to help the body make more stem cells. You'll usually have a dose of chemotherapy followed by injections of a growth factor drug called granulocyte-colony stimulating factor (G-CSF) for 5–10 days. You can often have these at home.

G-CSF helps the stem cells multiply and move out of the bone marrow into the blood. This process is called mobilisation and it takes several days. Blood tests will show whether your blood has enough stem cells for collection.

2 Stem cells collected



Stem cells are collected from your blood via a process called apheresis. You may have a needle called a cannula inserted into a vein in each arm, or you may need a special tube (central line) surgically inserted into your chest or neck.

During apheresis, blood is taken from your body, passed through a machine to remove the stem cells, and then returned to your body. This takes 3–4 hours and is usually done during a day visit to the hospital.

3 Stem cells preserved

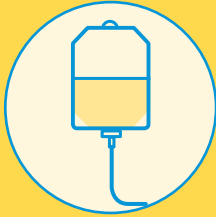


The stem cells are processed and frozen using liquid nitrogen. This is known as cryopreservation.

You will have a rest period at home for about a month before the next step.

More detailed information about stem cell transplants is available at leukaemia.org.au.

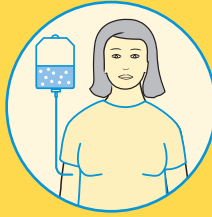
4 High-dose chemotherapy



In the week before the transplant, you'll go to hospital for high-dose chemotherapy to kill any remaining lymphoma cells. This will also destroy the stem cells in the bone marrow, making room for new stem cells to grow.

Side effects will be similar to those of standard chemotherapy but can be more intense. They may include nausea, diarrhoea, mouth sores, flu-like symptoms and high-risk of infections (see page 36).

5 Stem cells transplanted



A day or so after high-dose chemotherapy, your frozen stem cells are thawed and put back into your body (reinfused) using an intravenous drip. This process is similar to a blood transfusion and takes about an hour.

You may have stomach cramps and feel sick (nauseous), which can be managed with medicines.

6 Engraftment



Over the next couple of weeks, the new stem cells will develop into new blood cells, allowing your bone marrow to recover. This is called engraftment.

In most cases, you will stay in hospital for 1–4 weeks until your blood counts have returned to safe levels and you're well enough to go home. Once home, you'll need check-ups every week or so, but over time you'll need check-ups less often.



Sometimes the stem cells will be collected directly from the bone marrow by suction (aspiration) under general anaesthetic. This is called a bone marrow harvest. This is not a common procedure.

Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care.

Many people think that palliative treatment is for people at the end of their life; however, it can help people at any stage. It is about living as fully and comfortably as possible.

As well as slowing the spread of cancer, palliative treatment can relieve any pain and help manage other symptoms. Treatment may include short courses of radiation therapy, chemotherapy, targeted therapy or other medicines. If you are experiencing ongoing symptoms, ask for a referral to the symptom management or palliative care team.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, cultural, spiritual and social needs. The team also supports families and carers. Your care may be led by a specialist palliative care team or by your GP and a community nurse.

- ▶ See our *Understanding Palliative Care* or *Living with Advanced Cancer* booklets.



Key points about treatment

Treatment options

- Treatment is based on the type of non-Hodgkin lymphoma, the stage and how fast it is growing.
- Low-grade non-Hodgkin lymphoma grows very slowly. You may not need treatment right away, but will have regular check-ups instead. This is called watchful waiting.
- Intermediate- and high-grade non-Hodgkin lymphomas grow more quickly and need immediate treatment.

Main treatment

- Chemotherapy is the main treatment for aggressive non-Hodgkin lymphoma.
- Chemotherapy can be given in tablet form or intravenously. Treatment will be given as short sessions over several months, with rest periods of a few weeks between each session.

Further treatments

- Targeted therapy and steroid therapy are often combined with other treatments, such as chemotherapy.
- Radiation therapy uses targeted radiation to kill or injure cancer cells so they cannot multiply. It is given for about 3–4 weeks.
- A stem cell transplant may be an option if the lymphoma returns or does not respond to initial treatment. You will be in hospital for several weeks, and recovery will take time.
- Palliative treatment can be used at any stage of advanced non-Hodgkin lymphoma to relieve symptoms.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit cancercouncil.com.au.

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It can help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

Sexuality – 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.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See our *Fertility and Cancer* booklet.



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 that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

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.

► See our *Living Well After Cancer* booklet.

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, 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. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit **beyondblue.org.au**. For 24-hour crisis support, call Lifeline **13 11 14** or visit **lifeline.org.au**.

Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back and to manage any side effects of treatment.

Your follow-up schedule will depend on the type of non-Hodgkin lymphoma you were diagnosed with and the treatment you had. Your doctor may want to see you three or four times a year for the first couple of years. Check-ups will become less frequent if you have no further problems. Your doctor will talk to you about the best follow-up schedule for your situation.

During these check-ups, you will have a physical examination, blood tests and, possibly, scans. Your doctor will also discuss any new symptoms or late effects of treatment (see page 42). 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 becomes active again after a period of remission. 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 for a recurrence usually includes chemotherapy, targeted therapy and, sometimes, radiation therapy. If the cancer is more advanced or aggressive, your doctor may recommend a stem cell transplant combined with high-dose chemotherapy (see pages 43–45).



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often causes practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to a social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” Sam

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit our website at **cancercouncil.com.au**.

Practical help

Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit **cancercouncil.com.au/OC**.



Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council NSW	cancerCouncil.com.au
Cancer Council Online Community	cancerCouncil.com.au/OC
<i>The Thing About Cancer</i> podcast	cancerCouncil.com.au/podcasts
Cancer Australia	cancerAustralia.gov.au
Australasian Leukaemia & Lymphoma Group	allg.org.au
Australian Cancer Trials	australianCancerTrials.gov.au
Beyond Blue	beyondblue.org.au
Carer Gateway	carerGateway.gov.au
Carers Australia	carersAustralia.com.au
Carers NSW	carersNSW.org.au
Department of Health	health.gov.au
Healthdirect Australia	healthdirect.gov.au
Leukaemia Foundation	leukaemia.org.au
Lymphoma Australia	lymphoma.org.au
Radiation Oncology: Targeting Cancer	targetingCancer.com.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerResearchuk.org
Leukemia & Lymphoma Society (US)	lls.org
Lymphoma Research Foundation (US)	lymphoma.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on your situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a range of support available to help you with both the practical and emotional aspects of your caring role.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

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

Carers Associations – Carers NSW, a statewide organisation specifically for carers, can also provide support. Call 1800 242 636 or visit carersnsw.org.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit cancercouncil.com.au to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet and listen to our “Cancer Affects the Carer Too” podcast episode.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of non-Hodgkin lymphoma do I have?
- What stage is my lymphoma? How far has the cancer spread? How fast is it growing?

Treatment

- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the costs be reduced if I can't afford it?
- How will I know the treatment is working?
- Will the treatment cause any pain? How will it be managed?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Will the treatment affect my sex life or fertility?
- Are the latest tests and treatments for non-Hodgkin lymphoma available in this hospital?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

After treatment

- Who should I go to for my follow-up appointments?
- How often will I need check-ups after treatment?
- If the non-Hodgkin lymphoma returns, how will I know? What treatments could I have?



Glossary

abdomen

The part of the body between the chest and hips, which 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

A process that involves taking stem cells or tissues from one person and giving them to another.

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. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

antibody

Part of the body's immune system. A protein made by the blood in response to an invader (antigen) in the body.

apheresis

When blood is removed from the body and passed through a machine to separate a component such as stem cells. The rest of the blood is returned to the body.

autologous transplant

A process that involves taking stem cells or bone marrow from a person's own body and then giving them back following high-dose chemotherapy.

B-cell

A type of lymphocyte that makes antibodies to fight infection.

biopsy

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

blood cancer

A broad term for cancers that affect the blood, bone marrow and lymphatic system.

blood count

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

bone marrow

The soft, spongy material found inside bones. Bone marrow produces red blood cells, white blood cells and platelets.

bone marrow aspiration

The removal of a small amount of bone marrow liquid (aspirate) with a needle for examination under a microscope.

bone marrow trephine

The removal of a small piece of bone marrow tissue with a needle for examination under a microscope.

B symptoms

The symptoms of fever, night sweats and weight loss, which are sometimes caused by lymphoma.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

core biopsy

A type of biopsy where a sample is removed with a needle.

CT scan

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

cutaneous T-cell lymphoma

A type of non-Hodgkin lymphoma that affects the skin.

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 non-Hodgkin lymphoma that starts in lymph nodes in the neck, armpit or groin.

engraftment

The process by which transplanted stem cells develop into new blood cells. It takes about 2–4 weeks.

Epstein-Barr virus

A common human virus in the herpes family that may increase a person's risk of developing some types of cancer. Also called glandular fever or infectious mononucleosis.

excision biopsy

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

extranodal lymphoma

Lymphoma that has spread from the lymph nodes to other places in the body.

fertility

The ability to conceive a child.

follicular lymphoma

A slow-growing type of non-Hodgkin

lymphoma that affects B-cells. The cancer cells grow in circular groups called follicles.

grade

A description of how quickly cancer is likely to grow.

granulocyte-colony stimulating factor (G-CSF)

A growth factor drug used to help the body make more stem cells so they can be collected for a transplant, or to increase the number of white blood cells if they are low.

growth factor

A protein that stimulates the development and growth of cells.

haematologist

A doctor who specialises in studying and treating diseases of the blood, bone marrow and lymphatic system.

HIV (human immunodeficiency virus)

The virus that causes AIDS (acquired immune deficiency syndrome).

Hodgkin lymphoma

One of the two main groups of cancer of the lymphatic system. Also known as Hodgkin's disease.

immune system

A network of cells and organs that protects the body against attacks by foreign invaders, such as bacteria and viruses. Includes the lymphatic system.

infusion

A slow injection of a substance into a vein or other tissue.

intrathecal chemotherapy

Chemotherapy that is 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 cleans the blood and helps digestion.

lumbar puncture

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.

lymph

A clear fluid that circulates around the body through the lymphatic system. It carries white blood cells (lymphocytes) that help fight infection.

lymphatic system

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

lymph nodes

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

lymphocyte

A type of white blood cell that helps fight infection. Lymphocytes destroy bacteria, viruses and other harmful substances.

lymphoma

A type of blood 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 clear fluid known as lymph. They are found throughout the body.

mantle cell lymphoma

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

monoclonal antibodies

A group of targeted therapy drugs that lock onto a specific protein on the surface of cancer cells and interfere with the cells' growth or survival.

MRI scan

Magnetic resonance imaging scan. This scan uses magnetic fields and radio waves to take detailed pictures of the body.

neutropenia

A low level of neutrophils, a type of white blood cell. Neutropenia can make you more prone to infections.

NK-cell

The least common type of lymphocyte.

non-Hodgkin lymphoma

One of the two main groups of cancer of the lymphatic system. Also called non-Hodgkin's disease.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other symptoms.

pathologist

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

peripheral T-cell lymphoma

A type of non-Hodgkin lymphoma of T-lymphocytes that often starts as painless lymph nodes in the neck, armpit or groin.

PET-CT scan

Positron emission tomography scan combined with CT scan. In a PET scan, a person is injected with a small amount of radioactive glucose solution. This makes cancerous areas show up brighter on the scan.

platelets

One of three main types of cells found in the blood. Platelets help the blood to clot and stop bleeding.

precursor T-lymphoblastic lymphoma

A type of non-Hodgkin 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 expected outcome of a person's disease.

radiation oncologist

A doctor who specialises in treating cancer with radiation therapy.

radiation therapy

The use of targeted radiation, usually x-rays beams, to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy.

recurrence

The return of a disease after a period

of improvement (remission). Also known as relapse.

red blood cells

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

remission

When the signs and symptoms of the 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 may not mean that the cancer is cured.

response

When lymphoma shrinks or disappears after treatment.

small lymphocytic lymphoma

A type of slow-growing lymphoma affecting the B-cells. It is similar to chronic lymphocytic leukaemia.

small molecule inhibitors

A group of targeted therapy drugs that can get inside cancer cells and block proteins that tell the cells to grow.

spleen

An organ in the lymphatic system that makes lymphocytes and filters the blood.

stem cells

Unspecialised blood cells made in the bone marrow. They can grow into mature cells.

stem cell transplant

A treatment in which diseased blood cells are destroyed by high-dose chemotherapy or radiation therapy, then replaced by healthy stem cells. The

healthy stem cells may come from the bone marrow (bone marrow transplant), from the bloodstream (peripheral blood stem cell transplant) or from umbilical cord blood (cord blood transplant).

steroids

A class of drugs that are mostly used to reduce inflammation. Also called corticosteroids.

steroid therapy

Treatment with drugs to reduce inflammation, pain and swelling.

targeted therapy

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread. The two main types of targeted therapy at present are monoclonal antibodies and small molecule inhibitors.

T-cell

A type of lymphocyte that helps the body fight invaders (antigens) by killing them directly or helping B-cells make antibodies.

thrombocytopenia

A low level of platelets. It makes you more prone to bleeding and bruising.

thymus gland

A part of the lymphatic system. It helps produce white blood cells.

tissue

A collection of cells of similar type that make up an organ or structure in the body.

transfusion

The process of transferring body fluid (such as blood) from one person into another.

ultrasound

A scan that uses soundwaves to create a picture of part of the body.

watchful waiting

When a person does not need immediate treatment, but has their health monitored regularly, with the option of future treatment if necessary. Also called watch and wait.

white blood cells

One of three main types of cells found in the blood. White blood cells help fight infection. Types include neutrophils, lymphocytes and monocytes.

Can't find a word here?

For more cancer-related words, visit cancercouncil.com.au/words

References

1. Australian Cancer Network Diagnosis and Management of Lymphoma Guidelines Working Party, *Clinical Practice Guidelines for the Diagnosis and Management of Lymphoma*, Cancer Council Australia and Australian Cancer Network, Sydney, 2005.
2. Australian Institute of Health and Welfare (AIHW), Cancer data in Australia; *Australian Cancer Incidence and Mortality (ACIM) books: non-Hodgkin lymphoma*, AIHW, Canberra, 2018.



How you can help

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 other Pink events, 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 your local Cancer Council.



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 Australia (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, you can contact us through the National Relay Service. www.relayservice.gov.au



**Cancer
Council**
13 11 20

For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

For further information and details, visit our website, cancercouncil.com.au.

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