

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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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.

To make a donation to help fund vital cancer research and support services, visit cancercouncil.com.au or phone 1300 780 113.



Cancer Council NSW acknowledges Traditional Custodians of Country and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



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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 58 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 59). 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.¹⁻²



If you or your family have any questions or concerns, 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.

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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story

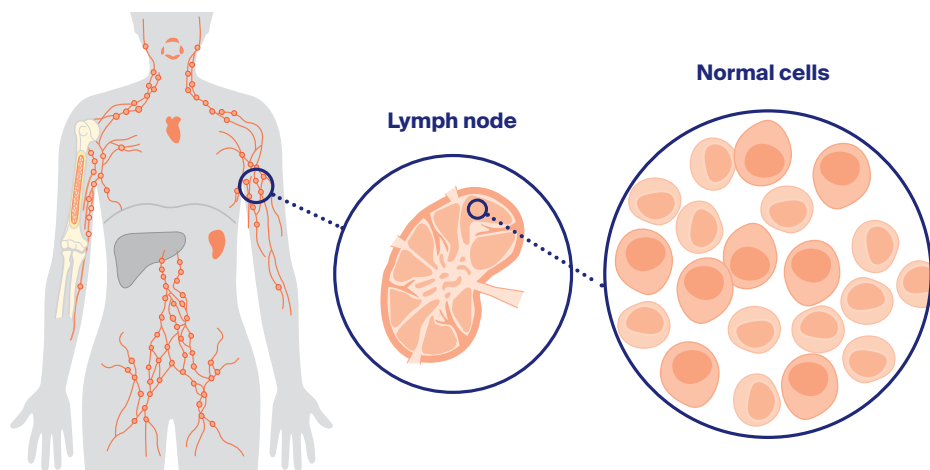
What is blood cancer?

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. These abnormal cells may turn into cancer.

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.

How lymphoma starts

Lymphoma usually starts in the lymph nodes.



Lymphatic system (see pages 6-7)

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 (tumour), usually in a lymph node.

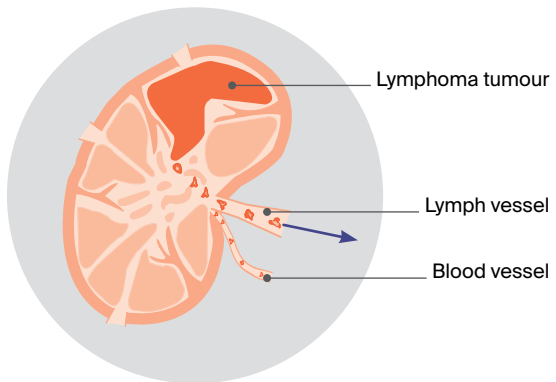
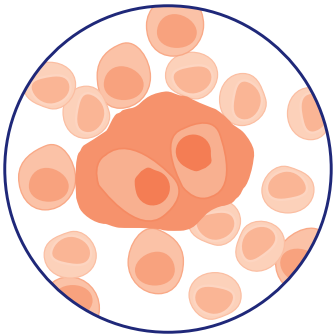
If abnormal lymphocytes continue to build up, they can spread through the lymph vessels to form a tumour in another part of the lymphatic system or, occasionally, in an organ outside the lymphatic system, such as the liver or lung.

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.

How lymphoma spreads

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

.....▶ **Abnormal cells**



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.

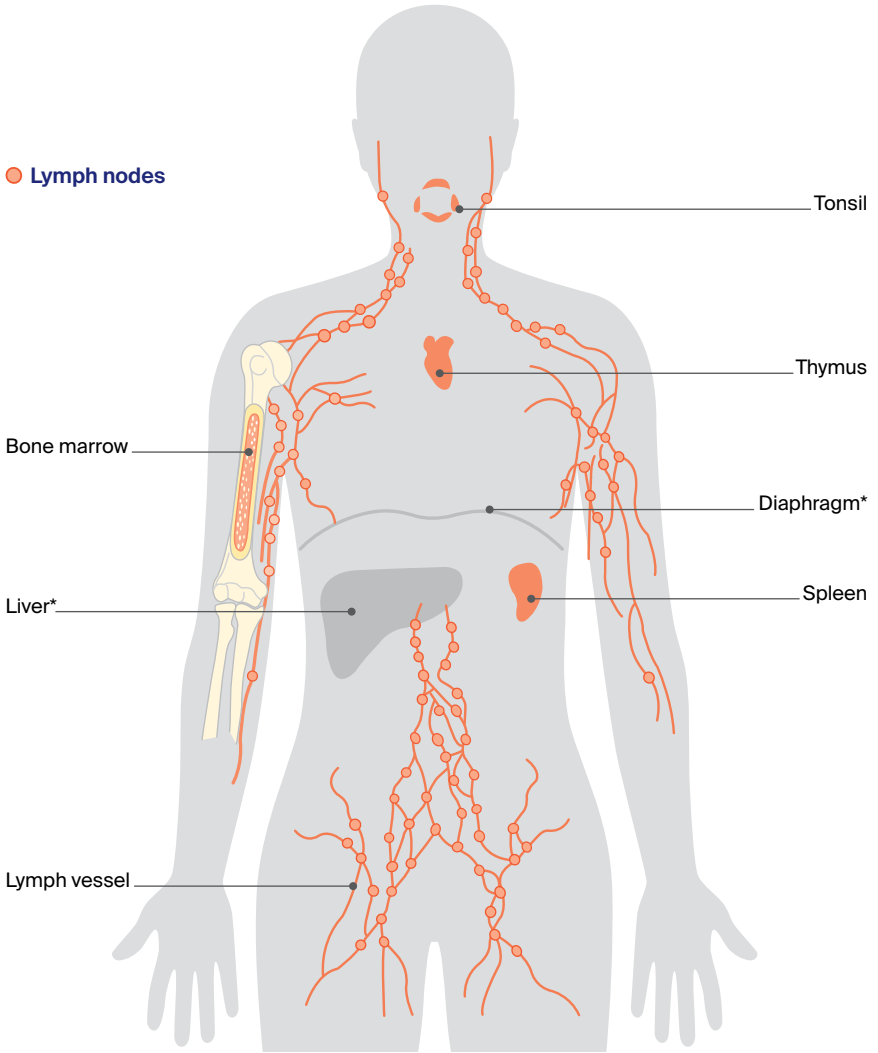
Lymph fluid – This clear fluid travels to and from the tissues in the body, carrying nutrients and taking away bacteria, viruses, abnormal cells and cell debris.

Lymph nodes – Also called lymph glands, these small, bean-shaped structures are made up of lymph tissue. There are about 600 lymph nodes all over the body. There are groups in the neck, underarms, chest, abdomen (belly) and groin. The lymph nodes filter lymph fluid 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 pages 8-9)
- thymus – a gland that helps produce a type of white blood cell known as T-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.

Parts of the lymphatic system



** Not part of the lymphatic system*

The role of blood cells

Bone marrow is the soft, spongy material inside bones. It makes 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 job to do (see diagram opposite).

White blood cells are part of the immune system and help fight infections. There are different types of white blood cells and they have different roles. The lymph nodes, lymph tissue and lymph fluid all contain the white blood cells known as lymphocytes.

Types of lymphocytes include:

- **B-cells** – make antibodies to fight infection
- **T-cells** – attack invaders (antigens) by killing them directly or by helping B-cells make antibodies
- **natural killer (NK)-cells** – rarer lymphocytes that specialise in killing cancer cells.

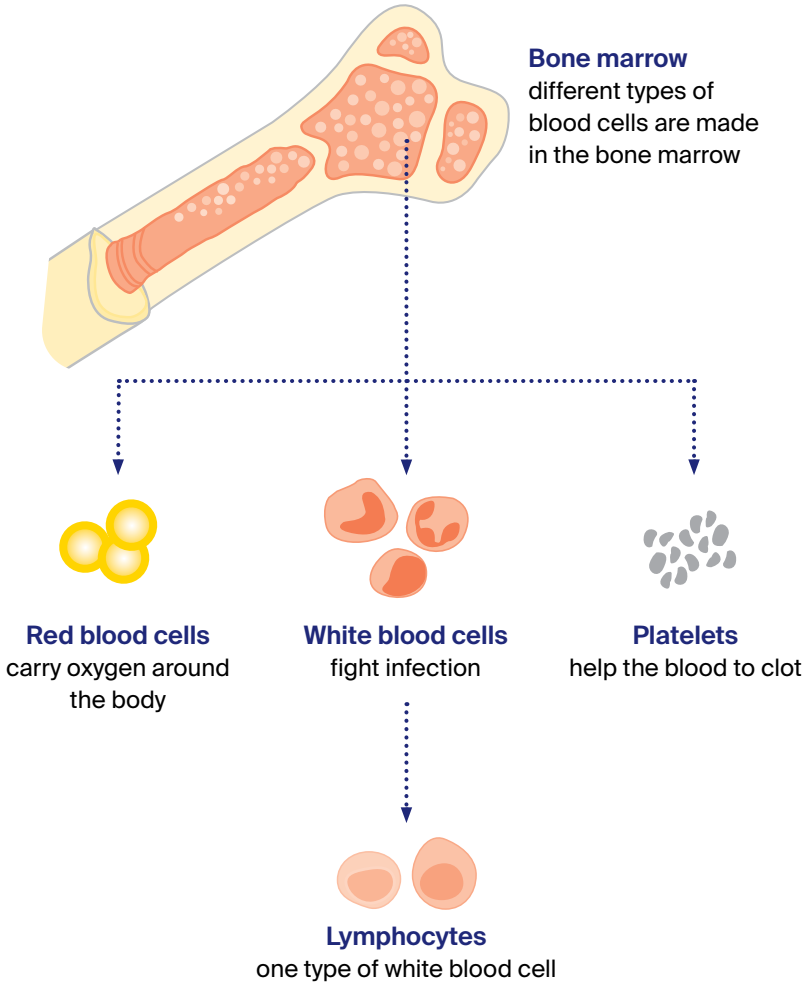
Diseases such as lymphoma or treatments such as chemotherapy can lower the number of blood cells in the body. This can cause:

- a low level of white blood cells (neutropenia), which makes you more likely to get infections
- a low level of red blood cells (anaemia), which may make you look pale and feel tired, breathless and dizzy
- a low level of platelets (thrombocytopenia), which means you bruise or bleed easily.

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

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.



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 used to be called non-Hodgkin’s disease. It is one of the two main groups of lymphoma. The other group is Hodgkin lymphoma (see 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.

Hodgkin lymphoma

There are two main types of lymphoma: non-Hodgkin and Hodgkin. Non-Hodgkin lymphoma is more common.

The two types of lymphoma 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.

Q: How common is it?

A: Each year in Australia, about 6400 people are diagnosed with non-Hodgkin lymphoma.³ It is more common in men than women. Most cases occur in adults aged 60 and older. Some types are more common in young adults and children. Non-Hodgkin lymphoma is the sixth most common cancer diagnosed in Australia.

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 in the lymph node (e.g. in the neck, underarm or groin).

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

- unexplained and frequent fevers
- drenching night sweats
- losing weight without trying.

Other symptoms may include feeling very tired, weak, drained and worn-out (known as fatigue) or, in rare cases, having itchy skin. Sometimes non-Hodgkin lymphoma starts in lymph nodes in deeper parts of the body, such as in the:

- stomach or spleen (causing bloating or back pain)
- chest (causing coughing and difficulty swallowing or breathing)
- brain and spinal cord (causing headaches or double vision).

These symptoms are common to many conditions, such as the flu or a virus. If you have any symptoms without an obvious cause, make an appointment to see your general practitioner (GP).

Q: What are the main types?

A: There are many different types of non-Hodgkin lymphoma, based on whether the lymphocyte affected is a B-cell, T-cell or NK-cell. It is also classified by how fast the lymphoma is growing such as

Types of B-cell lymphomas

Around 85% of all non-Hodgkin lymphomas are B-cell lymphomas. The most common types of B-cell lymphomas are diffuse large B-cell and follicular lymphoma.

Subtype	How does it grow?	How does it start?
diffuse large B-cell	fast-growing; intermediate-grade	the structure of the lymph node is disrupted and the lymphoma cells spread throughout the lymph node
follicular	usually low-grade	cells grow slowly in circular groups called follicles
small lymphocytic lymphoma (SLL)/ chronic lymphocytic leukaemia (CLL)	slow-growing; low-grade	SLL starts in the lymph nodes and CLL mainly starts in the bone marrow
marginal zone	slow-growing; low-grade	starts in the moist tissue (mucosa), which lines some body organs and cavities
mantle cell	can look low-grade, but act high-grade	develops in the outer edge (mantle zone) of lymph nodes
Burkitt	fast-growing; high-grade	lymph nodes enlarge in many parts of the body

slow-growing or fast-growing (see pages 24–25). Knowing the type of non-Hodgkin lymphoma you have will help your doctors plan your treatment.

Types of T-cell lymphomas

Around 15% of all non-Hodgkin lymphomas are T-cell lymphomas. The most common type of T-cell lymphoma is angioimmunoblastic, followed by anaplastic large cell lymphoma.

Subtype	How does it grow?	How does it start?
angioimmunoblastic	fast-growing; high-grade	occurs in lymph nodes, can cause skin rashes and produce abnormal proteins
anaplastic large cell	fast-growing; high-grade	can occur throughout the body or on the skin
peripheral T-cell	fast-growing; intermediate or high-grade	often occurs as widespread enlarged, painless lymph nodes
cutaneous (skin) T-cell	slow-growing; low-grade	primarily affects the skin; starts as red, scaly patches or raised bumps that can be itchy

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

“I’d noticed a lump in my neck but didn’t think much of it. When I started sweating so much at night that the sheets were drenched, I went to the doctor. After a biopsy I was told I had follicular lymphoma. I had no idea what that was, I’d never heard of it.” HELEN

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 of developing non-Hodgkin lymphoma is higher if your immune system has been weakened. This can happen if you have an autoimmune disease, such as rheumatoid arthritis or coeliac disease, or if you need to take medicines that suppress the immune system after an organ transplant.

Certain viruses – Some viruses can slightly increase the risk of developing non-Hodgkin lymphoma:

- *Helicobacter pylori* may increase risk of some types of lymphoma
- HTLV-1 (human T-cell lymphotropic virus 1) may increase the risk of some types of lymphoma
- hepatitis C
- Epstein-Barr virus
- HHV-8 (human herpesvirus 8).

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.

Breast implant associated anaplastic large cell lymphoma (BIA-ALCL) – Having a breast implant is linked with a rare type of lymphoma called breast implant associated anaplastic large cell lymphoma (BIA-ALCL). This includes having an implant for a breast enlargement or to reconstruct the breast after surgery for breast cancer.

Although it develops in the breast, BIA-ALCL is a type of lymphoma, not a type of breast cancer. The risk of developing an anaplastic large cell lymphoma following an implant is small. This can happen many years after having the implant. BIA-ALCL is more common with textured implants.

The Therapeutic Goods Administration (TGA) recommends that women who have implants monitor their breasts for any changes, such as sudden fluid collection. Every year, ask your surgeon or GP to check the implants. You can read more about BIA-ALCL on the TGA's website (visit tga.gov.au and search “BIA-ALCL for consumers”). The TGA also has an online breast implant hub, where information and support related to breast implants and their safety are updated as new information becomes available (visit tga.gov.au/hubs/breast-implants). If you are concerned, talk to your surgeon.

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 at every stage of your cancer care, visit cancer.org.au/cancercareguides/hodgkin-and-diffuse-large-b-cell-lymphoma. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

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, immunotherapy and other drug therapies; conducts stem cell transplants and CAR T-cell therapy
medical oncologist*	treats cancer with chemotherapy and other drugs such as targeted therapy; 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 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)
nurse or nurse practitioner	administers chemotherapy and other drugs; 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.

physiotherapist, occupational therapist	assist with physical or practical problems, including restoring movement and mobility, and recommending aids and equipment
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
pharmacist	dispenses medicines and gives advice about dosage and side effects
dietitian	helps with nutrition concerns and recommends changes to diet during treatment and recovery
palliative care specialists* and nurses	work closely with your GP and cancer specialists 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 examine your throat, tonsils, neck, chest and abdomen for swelling. Your GP may organise further tests or refer you to a specialist.

Lymph node biopsy

Taking some cells and tissue from an enlarged lymph node is the only way to find out why it's swollen. This is called a biopsy. There are different types of biopsy (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 where the node is, you'll have either a local or a 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

- Some cells and a small piece of tissue are removed from the lymph node using a hollow needle. This 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 a follow-up 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.

Immunophenotyping – This test looks for differences between types of cells. It does this by identifying markers called antigens, which are found on the surface of cells. Looking at the patterns of antigens can help your doctor work out what subtype of non-Hodgkin lymphoma you have.

Genetic tests (cytogenetic and molecular tests) – Cancer changes the genes of affected cells. These gene changes do not pass through families. They are only in the structure of the lymphoma cells, not in normal cells. Having tests to look for changes in the genes involved in lymphoma is becoming more standard.

The results of these genetic tests help doctors recommend the most suitable treatment options and work out the chance of the non-Hodgkin lymphoma coming back (relapsing) after a period of improvement (remission, see page 26).

One of the main tests used to look for particular gene changes in certain types of non-Hodgkin lymphoma is FISH (fluorescence in situ hybridisation). This test uses special dyes to identify abnormalities in chromosomes, such as deletions and translocations.

Further tests

Sometimes further tests are needed to find out whether the cancer has spread. This is called staging (see pages 24–25).

The following pages describe tests that are commonly used to help stage non-Hodgkin lymphoma. You may not need to have all these tests – most people will have blood tests and some imaging tests (see below). 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 the number of blood cells (blood count). Low blood counts before treatment may suggest 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).

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.

PET–CT scan – This specialised test combines a positron emission tomography (PET) scan with a non-contrast CT scan (see opposite page) 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 have diabetes. You will be encouraged to drink plenty of water to help the glucose solution leave your body.

The CT scan (see below) is used to help work out the precise location of any areas of concern shown on the PET scan.

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. While it can take 30–45 minutes to prepare for the scan, the scan itself takes only a few 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 or breastfeeding.

Ultrasound – An ultrasound uses soundwaves to create a picture of the internal organs. This test is most commonly used to guide the needle to the correct lymph node during a core biopsy (see page 18).

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.

Bone marrow biopsy

You may need to have a bone marrow biopsy to check whether lymphoma cells have 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. To help you feel relaxed, you may be offered light sedation or medicine that you breathe in through an inhaler.

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 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 it contains any lymphoma cells. Results are usually available within a couple of days to a week.

Lumbar puncture (spinal tap)

A lumbar puncture is a procedure used to collect a sample of fluid that surrounds the brain and spinal cord (cerebrospinal fluid). The sample is then tested for lymphoma cells. Doctors usually diagnose non-Hodgkin lymphoma with other tests, so most people will not need to have a lumbar puncture. Sometimes a lumbar puncture may 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, it will usually get better on its own. Check with your doctor whether you can take pain 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 18–23 help your doctors work out 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 don’t have any 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 is based on the look and shape of the cancer cells. The grade also describes how quickly the lymphoma is likely to grow and spread.

Non-Hodgkin lymphoma is separated into slow-growing (low-grade) and fast-growing (intermediate-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 the most common high-grade lymphoma. The table opposite describes the different grades.

“Calling the 13 11 20 helpline after I was diagnosed helped me take in the new information. I eventually joined a support group, which was also a great help.” LUISA

Stages of non-Hodgkin lymphoma

stage 1	One lymph node group is affected. This is either above or below the diaphragm.
stage 2	Two or more lymph node groups are affected either above or below the diaphragm.
stage 3	Lymph node groups both above and below the diaphragm are affected.
stage 4	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. Cancer cells look and act much like normal cells and are dividing slowly. 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 call this aggressive lymphoma. Cancer cells look and act less like normal cells. 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 achieving remission (see next page).

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 the 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 (relapses) of the disease during their lifetime, meaning they go in and out of remission. See page 53 for more information about treatment for relapsed lymphoma.

Key points about diagnosis

Initial test

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

Diagnostic test

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.
 - Imaging tests work out whether non-Hodgkin lymphoma has spread. These may include x-ray, CT or PET-CT scan, ultrasound and MRI scan.
 - Occasionally, you may need a bone marrow biopsy, which involves inserting a needle into the pelvic bone marrow to remove small samples of fluid and bone for examination.
 - Some people have a lumbar puncture to see if the lymphoma has spread to the brain or spinal cord.
-

Prognosis

- Your prognosis will depend on several factors, such as the stage and grade.
 - After initial treatment, most people go into remission but many people experience multiple episodes of non-Hodgkin lymphoma 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, as it may not 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 17) 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 says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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 58 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.

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 53).

Treatment options

Treatment will depend on the type of B-cell or T-cell lymphoma and how fast the lymphoma is growing (the grade, see pages 24–25).

Low-grade (slow-growing or indolent) lymphoma – You may not need treatment straightaway but have regular check-ups (watchful waiting, see next page). 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 or aggressive) lymphoma – You may need to be treated quickly. The main treatment option is chemotherapy.

Relapsed or refractory non-Hodgkin lymphoma – If lymphoma comes back after treatment (relapsed) or does not respond to treatment (refractory), you may be offered drug therapies (such as targeted therapy or immunotherapy) or a stem cell transplant.

What to do before treatment starts

Talk with your doctor about how you can 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 44). Your doctor may recommend you have some tests before, during and after treatment to check your heart function and limit the risk of damage.

Ask about fertility

Some treatments for non-Hodgkin lymphoma can cause infertility. This means you will no longer be able to conceive 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.

Get a dental check-up

Try to see a dentist before starting treatment to the head and neck area. If mouth and teeth issues are not treated, 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 24–25), 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).

Watchful waiting doesn't mean that nothing is done. You will see the doctor regularly to check for signs of the lymphoma progressing. Having treatment earlier than necessary can cause side effects. It can also make the lymphoma resistant to treatment, so if you need it later, it may not work as well. Many people who have no treatment for

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.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells or slow their growth. It can be used in various ways depending on the grade of non-Hodgkin lymphoma:

- low-grade – chemotherapy is often given with steroids and a targeted therapy or immunotherapy drug (see pages 39–41)
- high-grade – chemotherapy is the main treatment
- advanced – chemotherapy can be used as palliative treatment (see page 48).

Ways to have chemotherapy

Intravenous chemotherapy – Chemotherapy is most commonly given as a liquid infusion through a drip into a vein in your arm (intravenously). Chemotherapy 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:

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

Central venous access device – A thin plastic tube that remains in the vein throughout the course of treatment. Common types include:

- PICC (peripherally inserted central catheter) – a thin tube that is inserted into the upper arm

- port-a-cath (port) – a small device that is surgically inserted under the skin of the chest or arm
- central line (central venous catheter or CVC) – a thin tube with several openings that is inserted into a vein in the neck or chest.

Oral chemotherapy – Some chemotherapy drugs for non-Hodgkin lymphoma are given as tablets you swallow.

Intrathecal chemotherapy – Occasionally, chemotherapy is given into the fluid around the spine through a lumbar puncture (see page 23). 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.

Having chemotherapy

You will 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. Often chemotherapy is given over a few days, followed by a rest period of a few weeks between each session 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 even if tests show that the cancer is in remission after two or three cycles.

Common side effects of chemotherapy

The side effects of chemotherapy vary depending on the drugs given. Everyone reacts to chemotherapy differently. For more information about chemotherapy

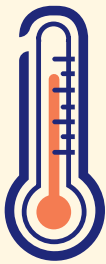
Fatigue



Severe tiredness and lack of energy (fatigue) may make you feel drowsy, exhausted or confused. These symptoms 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 with blood transfusions.

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

Increased risk of infections



Chemotherapy reduces your white blood cell level (neutropenia), making it harder for your body to fight infections. Viruses such as colds, flu and COVID-19 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 without any obvious cause and need to stay in hospital. Your doctor may recommend antibiotics. See page 36 for ways to reduce your risk of infection.

Nausea and vomiting

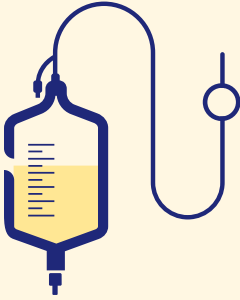


You will usually be given anti-nausea medicines with each chemotherapy session to stop you feeling sick (nauseous) or vomiting. These usually work very well. If you still feel sick or keep vomiting after using the prescribed medicine, let your nurse or doctor know so that another medicine can be tried.

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

and how to manage any side effects, call Cancer Council 13 11 20, or see our *Understanding Chemotherapy* booklet.

Bleeding or bruising



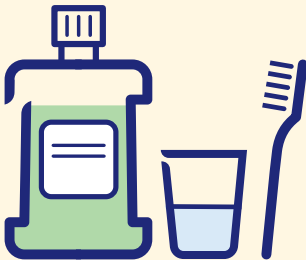
A drop in the number of platelets in your blood (thrombocytopenia) can cause heavy bleeding from small cuts or make you bruise easily. You may be given a platelet transfusion to increase your platelet count.

Constipation



Some chemotherapy drugs and medicines used for anti-nausea 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.

Mouth sores



Chemotherapy can damage the cells in the mouth causing mouth sores. These usually get better after treatment ends. Keeping your mouth clean will help prevent infections. Use a soft toothbrush to keep your mouth clean. Rinse your mouth four times a day with $\frac{1}{4}$ tsp bicarbonate of soda and $\frac{1}{4}$ tsp salt dissolved in a cup of warm water. If using a mouthwash, pick alcohol-free products.

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

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.

Ways to reduce your risk

To prevent the spread of infection:

- check with your doctor about having the flu and COVID-19 vaccines
- ask people close to you to consider having the flu and COVID-19 vaccines, and if they have a cold, flu or other contagious infection (e.g. COVID-19, measles or a cold sore), ask them 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
- 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 and 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 (also known as corticosteroids) are substances made naturally in the body. They can also be produced artificially and used as an anti-inflammatory drug. The most commonly prescribed steroid for non-Hodgkin lymphoma is prednisone.

Having steroids

You may be given steroids with chemotherapy to help chemotherapy work better, help destroy the lymphoma, and treat any nausea or vomiting. Corticosteroids are usually taken as tablets, 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 gradually go away after you stop taking the medicine.

When taken for a short period of time, steroids may increase your appetite, make you feel restless, make it harder to sleep or stay asleep (insomnia), cause weight gain and mood changes.

If you need to take steroids for several months, you may have a build-up of fluid in the body (known as fluid retention), 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 may prescribe a drug to help prevent ulcers while you are on steroid therapy. You may also be more likely to get infections (see opposite page).

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



Sheridan's story

In October 2020, I noticed some weight loss and changes in bowel movements. My GP initially thought it may be a non-cancerous condition called diverticulitis, but the symptoms got worse. I kept having scans until an ultrasound showed non-Hodgkin lymphoma.

The diagnosis was a terrible shock. Stepping into the cancer scene was frightening, but the cancer centre staff were wonderful.

I considered briefly not having chemotherapy, as I had heard how awful it was. I'm glad I changed my mind because, while it's different for everyone, for me it was lifesaving and managed well by the treatment team.

I had a catheter put into my upper chest after my first chemo, as my veins were small and it was difficult to get a cannula in. While it was painful to insert, the catheter turned out to be very useful. I needed a blood transfusion, and this was introduced via the line.

I came to understand that considerable advances have been made in the delivery of chemotherapy and, while it was unpleasant, side effects such as pain and nausea can be controlled through medication.

When I was told that I was in complete remission, I felt incredibly relieved but also a bit wary as I still was very thin and tired.

Having treatment during COVID-19 lockdowns was overwhelming. The restrictions meant I had to undergo blood tests, scans, chemo sessions and consultations with doctors on my own. No visitors were allowed in the hospital. Facing frightening procedures without family support made new experiences even more daunting.

I have to thank the doctors and staff as well as my husband and family for getting me to this stage. I realise how very lucky I have been.

Targeted therapy

Targeted therapy drugs attack specific features of 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 immune system makes proteins called antibodies to help fight infections. Monoclonal antibodies are manufactured versions of these natural antibodies. They target and attach to a protein found on cancer cells. This makes it easier for the body's immune system to find and destroy the cancer cells. In non-Hodgkin lymphoma, different monoclonal antibodies may be used for different proteins.

For CD20 proteins – Rituximab and obinutuzumab are used when the protein CD20 is found on B-cell non-Hodgkin lymphomas. Newer drugs for CD20 are becoming available in Australia. These work in the same way and are known as biosimilar drugs. These drugs do not work for T-cell or NK-cell lymphomas.

For CD30 proteins – Brentuximab vedotin is used when the protein CD30 is found in some B-cell lymphomas and some T-cell lymphomas.

Other targeted therapy drugs for non-Hodgkin lymphoma may be available through clinical trials (see page 29). Ask your doctor about the latest developments in targeted therapy for non-Hodgkin lymphoma.

Having monoclonal antibodies

Monoclonal antibodies are generally given through a drip into a vein. 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 let you know of any potential side effects before you start treatment. Some people may have a reaction (e.g. nausea, skin rashes and itching) during treatment or several hours after having these drugs. The risk of these reactions declines with every dose and is rare after the first dose. 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.

Small molecule inhibitors such as ibrutinib, idelalisib and venetoclax are used to treat some types of low-grade lymphoma that have not responded to treatment or have come back. In some cases, small

molecule inhibitors might also be an option if you are older.

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 you start treatment.



For more information, see our *Understanding Targeted Therapy* and *Understanding Immunotherapy* fact sheets or listen to our “New Cancer Treatments” podcast episode.

Immunotherapy

Immunotherapy uses the body’s own immune system to fight cancer. There are several types of immunotherapy, and each works differently.

Checkpoint immunotherapy – Pembrolizumab is a type of immunotherapy drug known as checkpoint inhibitor. It is available on the PBS for some types of relapsed or refractory non-Hodgkin lymphoma. It is given as an intravenous infusion every three weeks.

CAR T-cell therapy – A new type of immunotherapy used to treat relapsed and refractory lymphoma is chimeric antigen receptor (CAR) T-cell therapy. This boosts the ability of T-cells to fight cancer. T-cells are removed from the blood and altered so they can better recognise cancer cells. The altered T-cells are then returned to the blood through an intravenous drip (infusion). You will be in hospital for several weeks, and recovery will take time. At this stage, CAR T-cell therapy is available only in some hospitals in Australia.

Other immunotherapy drugs for non-Hodgkin lymphoma may be available through clinical trials (see page 29). Ask your doctor about the latest developments in immunotherapy for non-Hodgkin lymphoma.

Side effects of immunotherapy

Immunotherapy can cause inflammation in any organ of the body, leading to side effects such as fatigue, fever, skin rash and diarrhoea. The inflammation can lead to more serious side effects in some people, but this will be monitored closely and managed quickly.

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.

When radiation therapy is used

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 it may be combined 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 45).

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. In this case, the marks are put on the mask, 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. The radiation is given for 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 under a large machine called a linear accelerator (LINAC) 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.

Side effects of radiation therapy

The most common side effects of radiation therapy include:

- tiredness
- loss of appetite
- skin irritation
- hair loss at the treatment area.

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.

These side effects can build up towards the end of treatment, but most will be temporary. You will have regular reviews with the radiation oncologist or other team members to monitor your progress. 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 treatment will be carefully planned to reduce the risk of any of these late effects.

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 inherited a genetic risk. 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 before and during treatment to limit your risk of developing this condition. They will adjust your chemotherapy dose or change the drug if changes are seen. Radiation therapy to the chest area may also lead to heart disease.

Let your doctor know if you notice pain or tightness in the chest or feel your heart is beating too fast or too slowly.

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. Late side effects are less likely now because treatments have improved.

Stem cell transplant

If non-Hodgkin lymphoma returns (relapses) or does not respond to initial treatment (refractory disease), you may need a stem cell transplant. This involves a course of high doses of chemotherapy to help destroy the cancer cells. This can also damage your normal bone marrow cells, including 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) from which all blood cells develop. For non-Hodgkin lymphoma, stem cells are usually collected from the blood (peripheral blood stem cell transplant). Rarely, stem cells are collected from the bone marrow (bone marrow transplant) to treat non-Hodgkin lymphoma.

There are two main types of stem cell transplants.

Autologous transplant – This is 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 – This is 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. More detailed

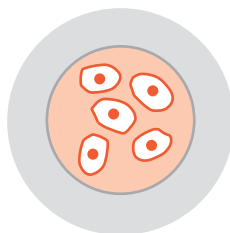
1. Stem cells stimulated



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 injections 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 made enough stem cells for collection.

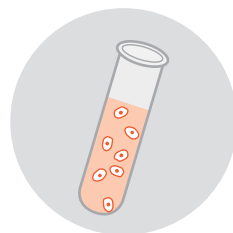
2. Stem cells collected



Stem cells are collected from your blood via a process called apheresis. You will have a needle called a cannula inserted into a vein in each arm, or you may need a special tube called a 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

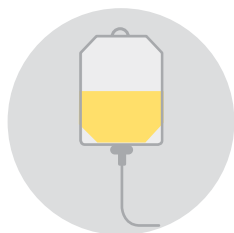


The stem cells are frozen using liquid nitrogen. This is known as cryopreservation.

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

information about stem cell transplants is available from the Leukaemia Foundation at leukaemia.org.au.

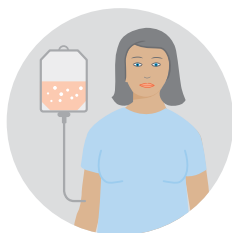
4. High-dose chemotherapy



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 pages 34–36).

5. Stem cells transplanted



A day or so after you have 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.

While the stem cells engraft, you're at risk of infection. In most cases, you will stay in hospital for 1–3 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. Over time, you'll need check-ups less often.

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 of advanced non-Hodgkin lymphoma. It is about living as long as possible in the most satisfying way you can.

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 aims 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 or listen to our advanced cancer podcast episodes.

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

- Some types of non-Hodgkin are treated with targeted therapy or immunotherapy drugs.
- Targeted therapy drugs and steroid therapy are often combined with other chemotherapy drugs.
- 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 or CAR T-cell therapy may be options 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 (also called supportive care) can be used at any stage of non-Hodgkin lymphoma treatment 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, may prevent successful treatment of the cancer and can be harmful. 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ 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. The experience of having cancer 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 may 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 can 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 non-Hodgkin lymphoma, 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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. 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 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 44). 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 comes back after a period of remission. This is known as a relapse. Sometimes non-Hodgkin lymphoma doesn't respond to treatment and this is known as refractory disease. Most people with relapsed or refractory non-Hodgkin lymphoma have more treatment.

Treatment for a lymphoma that has relapsed may include chemotherapy, targeted therapy, immunotherapy 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 45–47) or CAR T-cell therapy (see page 41). People with refractory disease may be offered a different treatment to the one they first had.

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 by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



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

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.

Practical help



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

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
Cancer Council podcasts	cancercouncil.com.au/podcasts
Guides to Best Cancer Care	cancer.org.au/cancercareguides
Australasian Leukaemia & Lymphoma Group	allg.org.au
Australian Cancer Trials	australiancancertrials.gov.au
Cancer Australia	canceraustralia.gov.au
Department of Health	health.gov.au
eviQ Cancer Treatments Online	eviq.org.au
Healthdirect Australia	healthdirect.gov.au
Leukaemia Foundation	leukaemia.org.au
Lymphoma Australia	lymphoma.org.au
My Aged Care	myagedcare.gov.au
Radiation Oncology: Targeting Cancer	targetingcancer.com.au
Services Australia	servicesaustralia.gov.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 the 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 wide range of support available to help you with 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 to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers NSW – Carers NSW, a statewide organisation for carers, can provide support. Call 9280 4744 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.

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.

antigen

Any substance that causes the immune system to respond, often prompting the blood to make antibodies.

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. For people with lymphoma, lymph node biopsy is the most common type.

biosimilar drug

Drugs that are similar, but not identical, copies of targeted therapy drugs.

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 stem cells that become 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 and bone marrow tissue with a needle for examination under a microscope.

B symptoms

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

checkpoint inhibitor

A type of drug treatment that uses the body's own immune system to fight cancer.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or with other treatments.

CAR T-cell therapy

Chimeric antigen receptor T-cell therapy. A process that involves taking T-cells from a person's own body and then giving them back after modifying them to boost their ability to fight cancer.

chronic lymphocytic lymphoma (CLL)

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

core biopsy

A type of biopsy where a tissue sample is removed with a wide 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.

genetic tests

Genetic tests aim to detect gene changes that are more commonly seen in certain types of cancer.

grade

A description of how quickly cancer is likely to grow. Low-grade lymphomas are slower growing (indolent); high-grade lymphomas are faster growing (aggressive).

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.

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.

immunotherapy

Treatment that uses the body's own immune system to fight cancer.

indolent

Lymphoma that is growing slowly.

intrathecal chemotherapy

Chemotherapy that is delivered through a lumbar puncture.

intravenous infusion

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

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 their 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 They specialise in killing cancer cells.

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.

peripheral T-cell lymphoma

A type of non-Hodgkin lymphoma of T-lymphocytes. It 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.

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-ray beams, to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy.

red blood cells

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

refractory disease

A disease that has not fully responded to initial treatment. Sometimes known as residual disease.

relapse

The return of a disease after a period of

improvement (remission). Also known as recurrence.

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 (SLL)

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 that is part of the lymphatic system. The spleen makes lymphocytes, filters the blood and destroys old blood cells.

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 features of cancer cells to stop the cancer growing and spreading. 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

A part of the lymphatic system. A gland that 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.

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2. National Comprehensive Cancer Network (US), *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): T-cell lymphomas, Version 1.2021*, October 2020, viewed 13 September 2021, available from nccn.org/guidelines.
3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, AIHW, Canberra, 2021, viewed 13 September 2021, available from aihw.gov.au/reports/cancer/cancer-data-in-australia.



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 Cancer Council NSW on 02 9334 1900.



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 experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

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

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit our website: cancercouncil.com.au

*This booklet is funded through the generosity of the people of NSW.
To support Cancer Council, call 1300 780 113.*

