

Understanding Lymphoma

A guide for people with cancer, their families and friends



For information & support, call **13 11 20**

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Understanding Lymphoma will be reviewed approximately every 3 years.

Check the publication date above to ensure this copy is up to date.

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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 booklet 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 stands by everyone living with cancer, protecting life's moments, for life. We support people affected by cancer when they need it most, speak out on behalf of the community on cancer issues, empower people to reduce their cancer risk, and find new ways to better detect and treat cancer. Together we are tackling cancer and leading NSW towards a cancer-free future. 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 and present.



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About this booklet

This booklet has been prepared to help you understand more about lymphoma, in particular, the 2 main groups, Hodgkin and non-Hodgkin lymphoma.

Many people feel shocked and upset when told they have lymphoma. We hope this booklet will help you, your family and friends understand how 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 lymphoma. It is based on clinical practice guidelines for Hodgkin lymphoma and 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

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SCAN ME

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 to heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one that is 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 3 main groups of blood cancers are:

- lymphoma
- leukaemia
- myeloma.

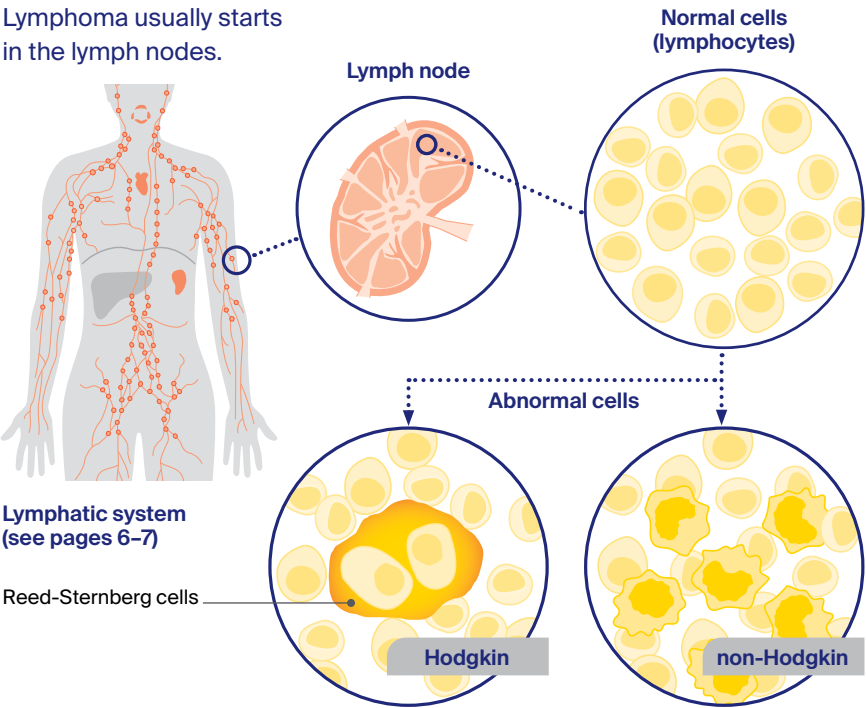
Lymphoma is cancer of the body's lymphatic system (see pages 6-7). It happens when white blood cells called lymphocytes become abnormal and grow uncontrollably to form a lump (tumour), usually in a lymph node.

If these abnormal lymphocytes continue to build up, they can spread and form a tumour in another part of the lymphatic system or, sometimes, in an organ outside the lymphatic system, such as the liver or lung. This is still lymphoma, not another type of cancer.

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.

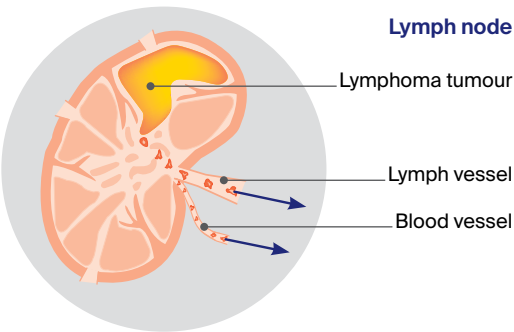
How lymphoma starts

Lymphoma usually starts in the lymph nodes.



How lymphoma spreads

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



The lymphatic system

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

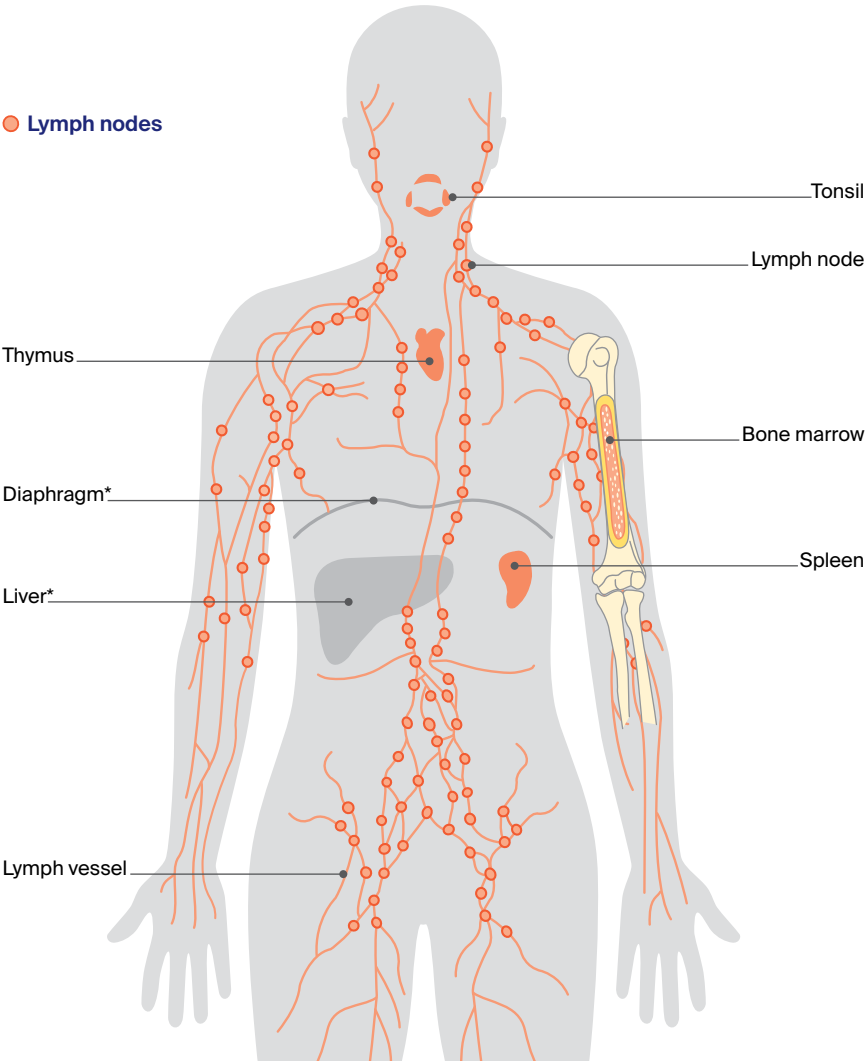
Lymph vessels – These thin tubes are found throughout the body and in organs such as the spleen, liver, thymus and bone marrow. Lymph vessels carry lymph fluid around the body.

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

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

- bone marrow – produces blood cells
- thymus – a gland that helps produce a type of white blood cell known as a T-cell
- spleen – stores white blood cells, filters waste products from the blood, and destroys old blood cells, abnormal cells and bacteria
- tonsils – trap germs entering through the nose and mouth
- digestive system – stores immune cells.

The lymphatic system in the body



** 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 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
- **NK-cells (natural killer cells)** – rarer lymphocytes that specialise in killing diseased cells, including cancer cells.

Diseases such as lymphoma and treatments such as chemotherapy (see pages 32–36) can lower the number of blood cells in the body and cause:

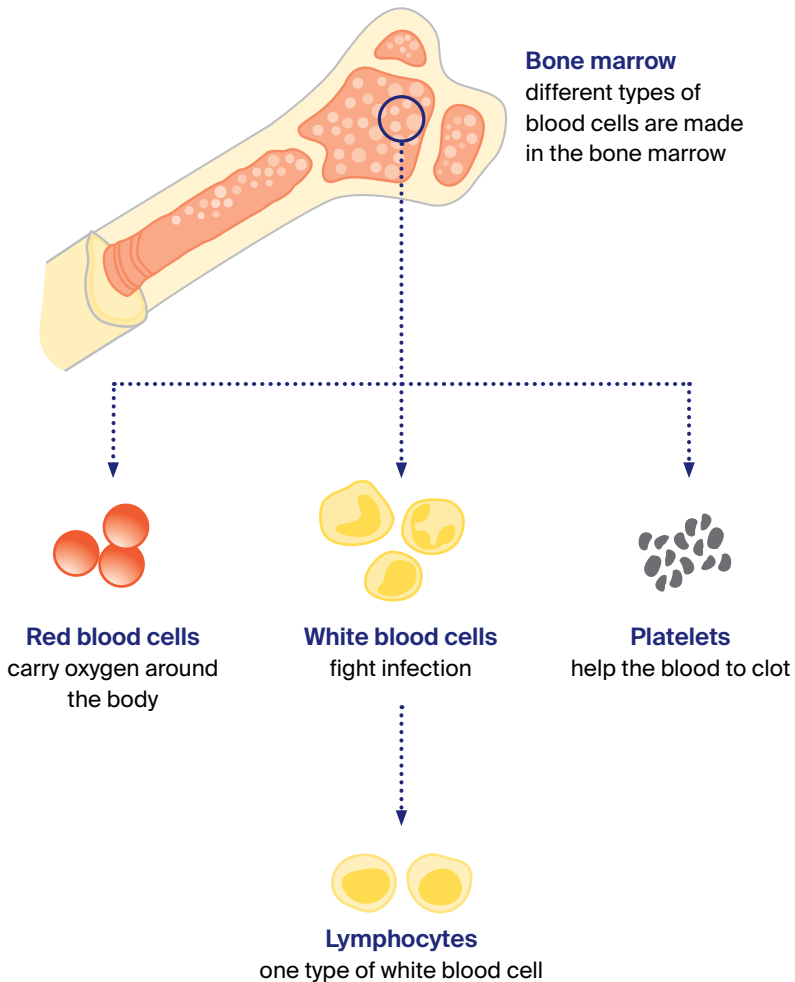
- a low level of white blood cells (leukopenia), which increases your risk of infection
- a low level of red blood cells (anaemia), which may make you look pale and feel tired, breathless and dizzy
- a low level of platelets (thrombocytopenia), which means you bruise or bleed easily.



For more information about lymphoma and other blood cancers, visit Lymphoma Australia at lymphoma.org.au or the Leukaemia Foundation at leukaemia.org.au.

Types of blood cells

The blood contains different types of cells, which all play different roles in the body.



Key questions

Q: What are the main types of lymphoma?

A: There are 2 main groups of lymphoma – Hodgkin lymphoma and non-Hodgkin lymphoma. Both are blood cancers that start in the lymphatic system and affect white blood cells called lymphocytes. Lymphocytes are special white blood cells that help your body fight off germs and stay healthy.

Both groups of lymphoma usually start in a lymph node in one or more places in the body. They can then spread through the lymphatic system from one group of lymph nodes to another. They can also spread to other lymph tissue, particularly in the bone marrow and spleen.

Sometimes, lymphoma can start in or spread to tissue in an organ outside the lymphatic system, such as the stomach, bowel, skin, bone, or brain and spinal cord (central nervous system). This is known as extranodal disease, and is more common with non-Hodgkin lymphoma.

Q: How are Hodgkin lymphoma and non-Hodgkin lymphoma different?

A: A key difference between Hodgkin and non-Hodgkin lymphomas is in the cells: Hodgkin lymphoma involves a special cell called the Reed-Sternberg cell, while non-Hodgkin lymphoma does not.

Hodgkin lymphoma is more common in teens and young adults, while non-Hodgkin lymphoma is more common in older people.

Q: How common are they?

A: Non-Hodgkin lymphoma is more common in Australia.

Hodgkin lymphoma – About 839 people are diagnosed with Hodgkin lymphoma in Australia each year. Hodgkin lymphoma can occur at any age, but it most commonly develops in younger people (with almost half of cases occurring in those aged 15–39), and in people aged 60 years and over. It is slightly more common in men than women.

Non-Hodgkin lymphoma – Almost 7000 people are diagnosed with non-Hodgkin lymphoma in Australia each year. It is more common in men than women, and most cases occur in people who are aged 60 and over.

Q: What are the main types?

A: Hodgkin lymphoma has 2 main types, while there are more than 60 types of non-Hodgkin lymphoma. Knowing the type helps doctors plan treatment.

Classical Hodgkin lymphoma occurs in about 95% of people with Hodgkin lymphoma. It features large abnormal cells called Reed-Sternberg cells, which have a distinctive appearance when seen under a microscope.

The other main type of Hodgkin lymphoma is called nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) and is rare. It tends to grow more slowly than classical Hodgkin lymphoma. It features abnormal cells that are sometimes called “popcorn cells” because of how they look.

For non-Hodgkin lymphoma, the type is based on whether the lymphocyte affected is a B-cell, T-cell or, rarely, NK-cell. It is also classified by how fast the lymphoma is growing (the grade, see pages 23–24). The most common types are listed in the tables below.

Common types of non-Hodgkin lymphoma (B-cell)

About 85% of all non-Hodgkin lymphomas are B-cell lymphomas. The most common types of B-cell lymphomas are diffuse large B-cell (about 1 in 3 cases) and follicular lymphoma (about 1 in 5 cases).

Subtype	Growth (grade)	How it starts
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 slow-growing; 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 often starts in the bone marrow
marginal zone	slow-growing; low-grade	starts in the moist tissue (mucosa) lining 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

Common types of non-Hodgkin lymphoma (T-cell)

About 15% of all non-Hodgkin lymphomas are T-cell lymphomas. Some of the most common subtypes are listed below. It can be challenging to diagnose the specific subtype of T-cell lymphoma, and it may take some time.

Subtype	Growth (grade)	How it starts
peripheral T-cell, not otherwise specified	fast-growing; intermediate-grade or high-grade	often occurs as widespread enlarged, painless lymph nodes
anaplastic large cell	fast-growing; high-grade	can occur throughout the body or on the skin
angioimmunoblastic (also called follicular helper T-cell lymphoma, angioimmunoblastic type)	fast-growing; high-grade	occurs in lymph nodes, can cause skin rashes and produce abnormal proteins
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’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.” HELEN

Q: What are the symptoms?

A: Hodgkin and non-Hodgkin lymphomas share many symptoms. Symptoms can be mild, making lymphoma hard to diagnose. Many other conditions can cause similar symptoms. However, if you have symptoms without any obvious cause, see your doctor.

Symptoms of each lymphoma

Symptoms	Hodgkin	non-Hodgkin
painless swelling in lymph nodes	usually in neck, chest or underarms	can occur in any lymph nodes in the body
fever*	●	●
night sweats that drench the bed*	●	●
unexplained weight loss*	●	●
fatigue	●	●
chest pain or coughing	●	●
abdominal pain or swelling	sometimes	●
chest pain and/or difficulty breathing	rarely	●

** These are called B symptoms and are specific signs that doctors look for when diagnosing and staging lymphoma. These symptoms help doctors understand how advanced the lymphoma is.*

Q: What are the risk factors?

A: The causes of both Hodgkin and non-Hodgkin lymphomas are largely unknown. However, research shows that certain factors can increase the risk of developing lymphoma.

Most people with known risk factors do not develop lymphoma, and some people who do get it have no known risk factors. Lymphoma is not contagious. Some risk factors include:

Weakened immune system – The risk of developing lymphoma is higher if your immune system isn't working properly. This can happen if you have an autoimmune disease, such as rheumatoid arthritis or coeliac disease, or if you take medicines that suppress the immune system after an organ transplant.

Certain infections – Infections with some viruses and bacteria can slightly increase the risk of developing some types of lymphoma. These infections include:

- *Helicobacter pylori*
- HTLV-1 (human T-cell lymphotropic virus 1)
- hepatitis C
- Epstein-Barr virus
- HHV-8 (human herpesvirus 8).

Family history – The risk is slightly higher if you have a close relative (e.g. parent or sibling) who has had lymphoma.

Breast implant associated cancer

Breast implant associated lymphoma (BIA-ALCL) is a rare type of non-Hodgkin lymphoma linked to some textured breast implants. It usually grows in the scar tissue or fluid around the implant, not in the breast itself. BIA-ALCL is not breast

cancer. Most people are treated successfully if it's found early.

For more information about BIA-ALCL, visit tga.gov.au and search "BIA-ALCL for consumers". You can also talk to your doctor.

Q: Which health professionals will I see?

A: Your general practitioner (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 what type of lymphoma you have.

Health professionals you may see

haematologist	diagnoses and treats diseases of the blood, bone marrow and lymphatic system; prescribes chemotherapy and other drug therapies; conducts stem cell transplants and CAR T-cell therapy
medical oncologist	treats cancer with drug therapies, such as chemotherapy, targeted therapy and immunotherapy; 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 your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
haematology nurse	administers chemotherapy and other drugs; provides care, information and support throughout treatment

If Hodgkin or 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 the GP and cancer team to help control symptoms and maintain quality of life

Diagnosis

If your GP suspects that you have lymphoma, they will feel the lymph nodes in your neck, underarms and groin for swelling. They may 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

If you have swollen lymph nodes, your doctor will organise a biopsy. This is when some cells and tissues are removed from the enlarged lymph node. A biopsy can be done in one of two ways – an excision biopsy or a core biopsy.

Excision biopsy

- The whole lymph node or part of it is removed with surgery. This may be done as day surgery, or you may stay in hospital for a few days.
- Depending on where the lymph node is, you'll have either a local or general anaesthetic.
- The wound is usually closed with stitches. These will be removed about a week later.
- An excision biopsy helps ensure an accurate diagnosis. It is the preferred way to take a biopsy for lymphoma because it reduces the risk that the sample will be too small to examine.

Core biopsy

- A hollow needle is inserted into the lymph node to remove some cells and a small piece of tissue. It is usually done as day surgery with a local anaesthetic.
- Ultrasound or CT scan may be used to guide the needle to the correct lymph node.
- A core biopsy is usually done when it is difficult to remove the lymph node or when 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. 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.

If the pathologist finds lymphoma cells, they can work out the type with further tests on the biopsy sample. These tests may include:

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. If lymphoma is found, immunophenotyping can work out the subtype by looking at the antigen pattern.

FISH tests – This stands for fluorescence in situ hybridisation. This test looks at changes inside lymphoma cells. It helps doctors confirm the type of lymphoma and choose the most suitable treatment.

Genomic and cytogenetic tests – These tests are more often used in diagnosing non-Hodgkin lymphoma. Genomic tests look for gene changes, faults or molecular targets. These gene changes are not the same as gene changes passed through families. Cytogenetic tests look for abnormalities in chromosomes.

Having tests to look for changes in the genes and chromosomes is becoming more common. The results of these tests help doctors recommend the most suitable treatment options. The results also help work out the chance of lymphoma coming back (relapsing) after a period of improvement (remission).

Further tests

If the biopsy of the enlarged lymph node shows that you have lymphoma, you may have further tests to find out the extent and type of lymphoma in your body. This is called staging (see pages 23–24).

The following pages describe tests that are commonly used to help stage lymphoma. You may not need to have all these tests – most people will have blood tests and at least one imaging test. Some tests may be repeated to check 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 (a full 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.



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

Imaging tests

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 the extent of the lymphoma.

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 cause you to feel hot all over and give you a strange taste in your mouth, and you could feel as if you need to pass urine (pee). These reactions usually go away after a few minutes but tell the clinical team if you feel unwell.

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.

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

For the PET scan, you will be injected in the arm with a glucose (sugar) solution containing a small amount of radioactive material. You will be asked to sit quietly for 30–90 minutes while the solution moves around your body. The scan itself takes about 30 minutes. Cancer cells take up more of the solution than normal cells and appear brighter on the scan.

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 is used to help work out the precise location of any areas of concern shown on the PET scan.

Chest x-ray – Some people may have an x-ray of the chest area to see if the lymphoma has spread to the lymph nodes in their chest or lungs. This is usually for people with symptoms such as shortness of breath or chest pain. An x-ray is painless and takes only a few minutes.

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 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. People with some types of pacemakers or other metallic objects cannot have an MRI.

Bone marrow biopsy

You may need to have a biopsy to check whether lymphoma cells have spread to the bone marrow. A bone marrow biopsy is more commonly used in non-Hodgkin lymphoma, particularly to help in staging.

A bone marrow biopsy is done in 2 steps:

Bone marrow aspiration – The doctor inserts a needle into the bone at the back of your pelvis to remove a small sample of fluid (aspirate) from the bone marrow. A local anaesthetic is given before.

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

A bone marrow biopsy takes about 30 minutes. It is usually done as an outpatient procedure, and you don't need to stay in hospital overnight.

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 check for lymphoma cells. Results are usually available in 2-7 days.

Staging and grading

Staging describes how far lymphoma has spread through the body. The tests described on the previous pages help your doctors work out the stage of the lymphoma.

The table on the next page explains the different stages of Hodgkin and non-Hodgkin lymphoma. Knowing the stage helps your doctor work out the best treatment for you.

As well as a number, each stage may be given a letter based on if you have specific symptoms. The letter A means you have no B symptoms (see page 14), while the letter B means you have the B symptoms.



Non-Hodgkin lymphoma is also given a grade, which is based on the look and shape of the cancer cells. The grade 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). They are treated in slightly different ways (see next page).

Stages of lymphoma (Hodgkin and non-Hodgkin)

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 divide 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.

Hodgkin lymphoma risk categories

Your doctor will consider the stage along with the results of blood tests and imaging scans to work out how Hodgkin lymphoma is likely to respond to treatment. This may be called the risk category.

Early-stage Hodgkin lymphoma may be categorised as “favourable” or “unfavourable”.

In unfavourable cases, more treatment may be needed to reduce the risk of relapse (when

disease returns after a period of improvement).

The signs of early-stage unfavourable Hodgkin lymphoma can include: many affected lymph nodes; larger lymph nodes (may be called bulky disease); inflammation in the blood; having B symptoms (see page 23).

Advanced Hodgkin lymphoma is generally categorised as high risk.

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).

It is not possible for anyone to predict the exact course of the disease. Several factors in assessing your prognosis include:

- your test results
- the type of lymphoma you have
- the stage and grade
- how quickly a tumour is growing
- 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.

Remission

Most people who are treated for lymphoma (including advanced disease) go into remission after treatment. This means the lymphoma symptoms 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 has not returned.

In a small number of cases, lymphoma may not respond to the first treatment. This is known as refractory disease. Sometimes it may come back (relapse or recur) after remission. See page 53 for more information about treatment for relapsed lymphoma.

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

Key points about diagnosis

Initial test

Your GP will physically examine you to check whether your lymph nodes are swollen.

Diagnostic test

- A biopsy of a swollen lymph node is the most common way to diagnose Hodgkin lymphoma and non-Hodgkin lymphoma.
 - All or part of the lymph node will be removed and the cells will be examined under a microscope.
 - Tests on the biopsy sample look for differences between types of cells and gene changes.
-

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 lymphoma has spread. These may include x-ray, PET-CT or 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, including the stage and grade.
 - After initial treatment, most people go into remission but some people experience multiple episodes of 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 pages 16–17) 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 lymphoma you have, the stage and grade, your age and general health, and your preferences.

The aim of treatment is to make the signs and symptoms of lymphoma reduce or disappear. This is called remission. Remission can last for a long period of time. Sometimes lymphoma becomes active again and further treatment is required. This is called a relapse (see page 53).

While Hodgkin and non-Hodgkin lymphomas are both types of cancer that start in the lymphatic system, they are often treated in different ways because some treatments work better for one type than the other. However, some treatments are used for both lymphomas – these include chemotherapy, steroid therapy and immunotherapy.

This chapter describes the types of treatments you may have. The table opposite shows what treatments can be used for Hodgkin lymphoma and non-Hodgkin lymphoma.

Watchful waiting

If you are diagnosed with low-grade non-Hodgkin lymphoma, you may not need treatment straightaway. Instead, you may have regular check-ups to monitor the lymphoma. This approach is called watchful waiting (or watch and wait). It is rarely used with Hodgkin lymphoma.

Watchful waiting does not mean that nothing is done. You will still see the doctor regularly to check for signs the lymphoma is progressing.

Having treatment earlier than necessary can cause side effects. 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.

Treatment options for each lymphoma

Treatment	Hodgkin (HL)	Non-Hodgkin (NHL)
watchful waiting (page 30)	rarely used	can be used with low-grade NHL
chemotherapy (pages 32–36)	a main treatment, often combined with radiation therapy	a main treatment, often combined with other drug therapies
radiation therapy (pages 37–39)	a main treatment, often combined with chemotherapy	can be used for low-grade NHL, and sometimes after chemotherapy
steroid therapy (page 39)	often used with chemotherapy	often used with chemotherapy
targeted therapy (pages 40–41)	used sometimes	used for some types of NHL
immunotherapy (pages 42–43)	checkpoint inhibitors may be used	may be used for some types of NHL
CAR T-cell therapy (page 43)	rarely used	used for some B-cell lymphomas that have come back or not responded to other treatment
stem cell transplant (page 44)	can be used if cancer comes back or does not respond to treatment	can be used if cancer comes back or does not respond to treatment

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 and type of lymphoma.

Chemotherapy can be given on its own or in combination with other drug therapies, such as steroids, targeted therapy and immunotherapy, or with radiation therapy.

Ways to have chemotherapy

Intravenous (IV) chemotherapy – Chemotherapy drugs are usually given as a liquid through a drip inserted into a vein (intravenous infusion). The drugs may be injected through a cannula, which is a small plastic tube inserted in a vein, or through a type of central venous access device (CVAD, see below).

The type of device used will depend on how often you need chemotherapy, how long it will take to give each dose, and the length of time you will be having chemotherapy.

Central venous access device – This is a thin plastic tube that stays 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 to give access to the veins
- 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 lymphoma are given as tablets that you swallow.



Occasionally, non-Hodgkin lymphoma is treated with chemotherapy that goes into the fluid around the spinal cord. This is called intrathecal chemotherapy. It's given through a lumbar puncture, where a doctor gently puts a needle into your lower back. The aim is to treat or stop lymphoma from spreading to the brain or spinal cord.

Having chemotherapy

You will usually have a combination of chemotherapy drugs given over 4–6 months. For Hodgkin lymphoma, the treatment is sometimes completed in 8 weeks.

The drug combination and treatment schedule will depend on the type of lymphoma. Usually, chemotherapy is given over a few days, followed by a rest period of a few weeks. This is called a cycle. The rest period lets your blood counts return to normal.

Throughout your 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 in your body, you will have regular blood tests to check your blood count, as well as 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 reduce your risk of infection.

Even if tests show the cancer is in remission after 2 or 3 cycles, chemotherapy may still be repeated several times to help reduce the chance of the lymphoma coming back.

Common side effects of chemotherapy

The side effects of chemotherapy vary depending on the drugs given. Everyone reacts to chemotherapy differently. You may have other side effects not

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 chemotherapy. Check with your doctor whether your fatigue is related to a low red blood cell count (anaemia). Anaemia may be treated with blood transfusions. If you are up to it, keeping active and exercising can help you feel less fatigued.

► See our *Understanding Fatigue and Cancer* fact sheet.

Nerve effects



Some chemotherapy drugs can cause nerve damage (peripheral neuropathy). Symptoms can include tingling, pain or loss of feeling in your fingers and/or toes, and muscle weakness in your legs. These side effects usually disappear after treatment ends, though they can last a long time or even be permanent.

► See our *Understanding Peripheral Neuropathy and Cancer* fact sheet.

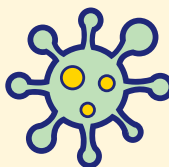
Constipation



Some chemotherapy drugs and anti-nausea medicines can cause constipation. Ways to prevent constipation include drinking 6–8 glasses of water a day, eating a high-fibre diet and getting daily exercise.

Your treatment team may also suggest or prescribe a suitable laxative or stool softener.

Increased risk of infections



Chemotherapy reduces your white blood cell level (neutropenia), making it harder for your body to fight infections. See page 36 for ways to reduce your risk of infection.

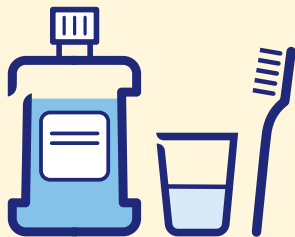
mentioned here. For more information, call Cancer Council 13 11 20, or see our *Understanding Chemotherapy* booklet.

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.

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 after each meal to keep your mouth clean. If using a mouthwash, pick alcohol-free products.

► See our *Understanding Mouth Health and Cancer Treatment* fact sheet.

Hair loss



You may lose some hair from your head, eyebrows and eyelashes. Your hair will grow back after treatment. You can wear a scarf, a hat or a wig. You may be able to borrow a wig from a wig library. If you have private health insurance, your fund may cover part of the cost of a wig.

► See our *Understanding Hair Loss* fact sheet.

Nausea and vomiting



You will usually be given anti-nausea medicines before having chemotherapy to stop you feeling sick 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 for People Living with Cancer* booklet.

Taking care with infections

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

Ways to reduce your risk

To prevent the spread of infection:

- check with your doctor about having vaccines for the flu and COVID-19
- ask people close to you to consider having the flu and COVID-19 vaccines
- ask family and friends with a cold, COVID-19, flu or other contagious infection (e.g. cold sores, measles, chickenpox) 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 very crowded places, such as shopping centres or public transport in peak hour
- wash your hands with soap and water before preparing food, 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 foods (fish, seafood, meat and 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
- a burning or stinging feeling when urinating (peeing)
- a severe cough or sore throat
- shortness of breath
- vomiting that lasts more than a few hours
- severe belly pain, constipation or diarrhoea
- unusual bleeding, such as blood in your urine (pee) or black bowel movements (poo) or nosebleeds
- ongoing faintness or dizziness, and rapid heartbeat
- any tenderness, redness or swelling around the site of your intravenous chemotherapy device
- any sudden decline in your health.



Sheridan's story

I noticed some weight loss and changes in bowel movements. An ultrasound showed it was non-Hodgkin lymphoma.

I considered briefly not having chemotherapy, as I had heard how awful it was. I'm glad I changed my mind because, for me, it was life-saving 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.

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.

When I was told I was in complete remission, I felt incredibly relieved.

Radiation therapy

Radiation therapy (also known as radiotherapy) uses radiation to kill or damage cancer cells so they cannot grow, multiply or spread. It can be used to treat both groups of lymphoma but is more commonly used for Hodgkin lymphoma.

You may have radiation therapy for:

- **Hodgkin lymphoma** – as part of the initial treatment. It is often used in combination with chemotherapy
- **non-Hodgkin lymphoma** – on its own to treat low-grade lymphoma, or after chemotherapy to treat high-grade lymphoma.

The type of radiation therapy used to treat both non-Hodgkin and Hodgkin lymphomas is called external beam radiation therapy (EBRT). It is delivered using a machine called a linear accelerator, which produces high-energy x-rays to kill or damage cancer cells.

It is commonly focused on an area of lymph nodes. It can also be given to the whole body (total body irradiation) before a stem cell transplant.

Having radiation therapy

About 1-2 weeks before you start treatment, your radiation oncologist will use the results of your imaging scans to help work out the lymph node areas to treat with radiation.

Radiation therapy usually starts a few weeks after your last chemotherapy cycle. The actual treatment takes only 1-2 minutes, and you will not be able to see or feel the radiation. Usually, treatments are delivered daily from Monday to Friday.

Most people have radiation therapy as an outpatient. This means you do not stay in hospital, but travel to the hospital or treatment centre for each session. You may have treatment for 1-4 weeks. The radiation oncologist will discuss your treatment schedule with you.

Side effects of radiation therapy

The most common side effect is tiredness. Talk to your treatment team about suitable exercise during radiation therapy – improving fitness can help reduce tiredness.

Radiation therapy can also cause skin changes such as red, dry and itchy skin at the treatment area. Other side effects will depend on the part of the body being treated.

Side effects can build up towards the end of the course of treatment, but most will be temporary. Radiation therapy can also cause some long-term or late effects, which can appear months or years after treatment ends (see pages 45–46). You will have regular reviews with the treatment team. Talk to them about any side effects that concern you.

► See our *Understanding Radiation Therapy* booklet.

Steroid therapy

Steroids (also known as corticosteroids) are substances made naturally in the body. They can also be produced artificially and used to reduce inflammation (redness, swelling and/or pain). The most commonly prescribed steroid for both Hodgkin and non-Hodgkin lymphomas is prednisolone.

Having steroids

You may be given steroids with chemotherapy to increase the effect of the chemotherapy, help destroy the lymphoma, and treat any nausea or vomiting caused by the chemotherapy. Steroids are usually taken as tablets, but can also be given into a vein (intravenously).

Side effects of steroid therapy

Steroid therapy can cause various side effects, which depend on the dose prescribed and how long you take steroids. 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), and 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 *Taking care with infections* on page 36).

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

Targeted therapy

Targeted therapy drugs attack specific 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. Targeted therapy is currently used less often to treat Hodgkin lymphoma.

The body's immune system makes proteins called antibodies to help fight infections. Monoclonal antibodies are manufactured versions of these natural antibodies. They lock onto a protein on the surface of cells or surrounding tissues to affect how cancer cells grow and survive.

Because they work with the immune system, monoclonal antibodies may also be considered a form of immunotherapy (see page 42). There are different drugs available, and your haematologist will discuss which combination of drugs is best for your situation.

Monoclonal antibodies are generally given through a drip into a vein (IV infusion). They are usually combined with chemotherapy and are commonly given in repeating cycles. Talk to your doctor about your specific treatment schedule.

Small molecule inhibitors

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

Small molecule inhibitors are used to treat some types of low-grade non-Hodgkin lymphoma that have not responded to treatment or have come back. In some cases, they may also be an option if you are older.

Some small molecule inhibitors can also help the immune system work

better against cancer. This means they can sometimes be a form of immunotherapy (see next page).

These drugs can 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.

Side effects of monoclonal antibodies

Your doctor will explain the potential side effects before you start treatment. Side effects can include headache, fatigue, low white and red blood cells, flu-like symptoms and an increased risk of abnormal bleeding. You will have regular check-ups during treatment.

Some people react to the infusion process (e.g. nausea, skin rashes and itching) during treatment or several hours after the infusion. Reactions are more common with the first infusion, with the risk declining after every dose. You may be given medicine to help prevent such a reaction.

It is important to report any side effects to your doctor straightaway. If left untreated, some symptoms can become life-threatening.

Immunotherapy

Immunotherapy uses the body's own immune system to fight cancer. There are 2 main types of immunotherapies used to treat lymphoma – checkpoint inhibitors and CAR T-cell therapy. Your haematologist will discuss which is best for you.

Checkpoint inhibitors

Checkpoint inhibitors are drugs that help the immune system recognise and attack cancer cells. This type of immunotherapy can be used to treat Hodgkin lymphoma. At this stage, checkpoint inhibitors are not used to treat non-Hodgkin lymphoma.

To work out if checkpoint inhibitor therapy is an option for you, your cancer specialist will consider the type and stage of cancer, your treatment history, future treatment options and your overall health.

Checkpoint inhibitors are given as a liquid through a drip inserted into a vein (intravenous infusion). They are usually given in repeating cycles, with rest periods of 2–6 weeks between cycles.

How often and how long you have the treatment depends on the type of cancer, the type of checkpoint inhibitor, how the cancer responds to the treatment, and what side effects you may experience. People can stay on checkpoint inhibitors for up to 2 years.

Checkpoint inhibitors can take weeks or months to start working. Sometimes they keep working long after treatment stops, but this varies from person to person.

Side effects – Because immunotherapy drugs act on the immune system, they can sometimes cause the immune system to attack healthy

cells in any part of the body. This can lead to a variety of side effects such as skin rash, diarrhoea, breathing problems, inflammation of the liver, hormone changes and temporary arthritis. Your doctor will discuss possible side effects with you.

CAR T-cell therapy

Chimeric antigen receptor (CAR) T-cell therapy is a type of immunotherapy used to treat some types of non-Hodgkin lymphoma. This therapy works by boosting the ability of T-cells to fight cancer.

To make CAR T-cells, your own T-cells are removed from your blood and changed so they can better recognise cancer cells. A few weeks later, the changed T-cells are returned to the blood through an intravenous drip (IV infusion). You will stay in hospital for several weeks, and recovery will take time.

CAR T-cell therapy is available only for some types of B-cell lymphomas that have come back or have not responded to other treatment. If CAR T-cell therapy is an option, you may be referred to a specialist centre for treatment.

Side effects – CAR T-cell therapy can cause the immune system to react, causing cytokine release syndrome (CRS). Symptoms of CRS include a high temperature, fast heart rate, low blood pressure, changes to your blood cell count, and breathing difficulties.

CAR T-cell therapy can also affect the nervous system, causing side effects in the brain, such as headaches and confusion. Your doctor will discuss possible side effects with you and how long they may last. Most side effects can usually be managed, but it's important to let your doctor know if you have them.

Stem cell transplant

If lymphoma returns (relapses) or does not respond to initial treatment (refractory disease), you may have a stem cell transplant. This is when diseased blood cells are destroyed by high-dose chemotherapy and replaced with blood stem cells.

Stem cells are an unspecialised early form of blood cells (see page 8). They are usually collected from the blood (peripheral blood stem cell transplant). Rarely, stem cells are collected from the bone marrow through a bone marrow transplant.

Stem cell transplants are used less often now than in the past. It is a demanding treatment and is not suitable for everyone, especially people with other health problems. The entire procedure, including recovery, can take months.

There are 2 main types of stem cell transplants.

Autologous transplant – This is when your stem cells are removed from your blood, processed and later put back (reinfused) into your body. This is the most common type of transplant used to treat lymphoma. An autologous transplant is done in several steps over several months.

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 lymphoma.

To work out whether a stem cell transplant is suitable for you, your haematologist will consider your general health, age, the type of lymphoma, how fast it's growing and how it responds to treatment.

Fertility and treatment for lymphoma

Some types of chemotherapy and radiation therapy can affect the ability to have children naturally.

If you produce sperm, you may not make as many. If you have periods, they may become irregular or stop permanently (menopause). Most people treated for lymphoma don't

become infertile. Your doctor will talk to you about the risk and refer you to a fertility specialist if it may be an issue for you. If there is enough time before treatment begins, you may be able to preserve some semen or freeze embryos or eggs.

► For more information, see our *Fertility and Cancer* booklet.

Late effects of treatments

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.

With improved staging and treatment of lymphoma, late effects are less likely than in the past. Your doctor will talk to you about any possible late effects before treatment starts.

When treatment finishes, talk to your doctors about your risk of developing late effects from treatment and how this will be monitored. Ask for a written summary of your treatments so you have this on hand if needed. It is important that you talk to your doctors about any symptoms that appear, even many years after treatment.

Second cancers – Occasionally, many years after successful treatment for lymphoma, some people develop a new, unrelated cancer. This may be either a new form of lymphoma or leukaemia, or a type of solid cancer.

Sometimes a second cancer develops due to 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 – There can be a higher risk of problems with the heart and blood vessels after cancer treatment. This is called cardiovascular disease or heart disease.

When working out the best treatment for you, your doctors will check your heart health. This is to try to find a therapy that is effective in treating the cancer while causing the least amount of damage to the heart and blood vessels.

Certain chemotherapy, targeted therapy and immunotherapy drugs may cause heart problems. Radiation therapy to the chest can also cause problems with the heart.

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

► See our *Understanding Heart Health and Cancer* fact sheet.

Thyroid problems – Radiation therapy to the neck area may cause an underactive thyroid, and you may need to take daily thyroid hormone replacement pills. Common symptoms of an underactive thyroid are fatigue, weight gain and bowel problems.

Early menopause and infertility – Some chemotherapy drugs can damage your ovaries or testicles. This might lead to early menopause in women, and reduced fertility in both men and women (see page 45).



Amy's story

I was 40, fit, and working full-time when I was diagnosed with classical Hodgkin lymphoma.

The only symptom I noticed was a lump in my neck. I may not have thought anything of it, but it was on my radar because a colleague, who was the same age as me, had recently been diagnosed with Hodgkin lymphoma.

Waiting for the biopsy results was terrible. I was on holidays for the first 10 days, and tried to put it to the back of my mind. About 12 days after the biopsy, I called my GP and they tracked down the results.

The diagnosis of Hodgkin lymphoma came just as I was about to start IVF, so this felt like a double whammy. I spoke to my haematologist about delaying the start of my treatment until I could harvest some eggs. Fortunately, for my type of cancer, I was able to do this. My eggs were harvested on a Friday and I started chemotherapy on the following Monday.

I was on a clinical trial for a new combination of chemotherapy drugs that aimed to reduce the treatment time to only 3 months.

A port-a-cath was inserted so I didn't need to have a cannula put in every time I had the chemo. I found the insertion painful, but it was beneficial to have the port throughout the treatment.

I continued working through the treatment, and this was challenging. The nausea and anxiety on treatment days did increase as each cycle progressed.

I found it difficult to manage, particularly on the second day of the chemo cycle when they give you a drug known as "the red devil". I also had really low energy levels and needed a blood transfusion.

I am in clinical remission and my PET-CT scans have all shown that the treatment was successful. I'm still working and I'm back at the gym, but the brain fog is lingering.

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 lymphoma to improve quality of life – it does not mean giving up hope. Palliative treatment can help some people with advanced lymphoma live well and with few symptoms for many months or years.

As well as slowing the spread of cancer, palliative treatment can relieve 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 *The Thing About Advanced Cancer* podcast series.

Key points about treatment

Treatment options

- Treatment is based on the type of 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, called watchful waiting.
- Intermediate-grade and high-grade (aggressive) non-Hodgkin lymphomas grow more quickly and need immediate treatment.
- Hodgkin lymphoma is often treated with a combination of chemotherapy and radiation therapy.

Main treatment

- Chemotherapy is the main treatment for Hodgkin lymphoma and aggressive non-Hodgkin lymphoma. It is often combined with radiation therapy for Hodgkin lymphoma.
- Chemotherapy may be given in tablet form or intravenously.
- Side effects of chemotherapy include fatigue, nausea, increased risk of infections and hair loss.
- Steroids may be used to increase the effect of chemotherapy and treat nausea and vomiting.
- Radiation therapy can be used to treat both groups of lymphoma but is more commonly used to treat Hodgkin lymphoma.

Further treatments

- Some types of lymphoma are treated with targeted therapy or immunotherapy drugs.
 - CAR T-cell therapy is a type of immunotherapy used to treat some types of non-Hodgkin lymphoma.
 - A stem cell transplant may be an option if the lymphoma returns or does not respond to initial treatment.
 - Palliative treatment can be used at any stage of 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 for People Living with 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 and 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 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.

Sex and intimacy – Cancer can affect your sex life 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 *Sex, 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 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 have regular appointments to monitor your health, manage any long-term side effects and check that the lymphoma hasn't come back or spread.

Your follow-up schedule will depend on the type of lymphoma you were diagnosed with and the treatment you had. Your doctor may want to see you 3–4 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 your follow-up schedule.

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 pages 45–46). Between follow-up appointments, let your doctor know immediately about any health problems or new symptoms.

What if lymphoma returns?

For some people, lymphoma comes back after a period of remission. This is known as a relapse. Sometimes lymphoma doesn't respond to treatment, and this is known as refractory disease. Most people with relapsed or refractory lymphoma will have more treatment.

Treatment for a relapse may include chemotherapy, targeted therapy, immunotherapy and, sometimes, radiation therapy. Sometimes, if the cancer is more advanced or aggressive, your doctor may recommend that you have a stem cell transplant combined with high-dose chemotherapy (see page 44) or CAR T-cell therapy for non-Hodgkin lymphoma (see page 43). People with refractory disease may be offered a different treatment than 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.

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

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 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support



If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Council 13 11 20.

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
eviQ (cancer treatment information)	eviq.org.au
Healthdirect Australia	healthdirect.gov.au
Leukaemia Foundation	leukaemia.org.au
Lymphoma Australia	lymphoma.org.au
Radiation Oncology: Targeting Cancer	targetingcancer.com.au
Services Australia (including Centrelink and Medicare)	servicesaustralia.gov.au

International

American Cancer Society	cancer.org
Blood Cancer United (US)	bloodcancerunited.org
Cancer Research UK	cancerresearchuk.org
Lymphoma Research Foundation (US)	lymphoma.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov



Caring for someone with lymphoma

You may be reading this booklet because you are caring for someone with lymphoma. 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 02 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 lymphoma do I have?
 - What stage is the lymphoma? How far has it spread? How fast is it growing?
 - Are the latest tests and treatments for this type of lymphoma available in this hospital?
 - Are there clinical guidelines for this type of cancer?
-

Treatment

- What treatment do you recommend? What is the aim of the treatment?
 - Are there other treatment choices for me? If not, why not?
 - If I don't have the treatment, what should I expect?
 - How long do I have to decide?
 - 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 we know the treatment is working?
 - Are there any clinical trials or research studies I could join?
 - Will treatment affect my fertility?
-

Side effects

- What are the risks and possible side effects of each treatment?
 - Will I have a lot of pain? What will be done about this?
 - Can I work, drive and do my normal activities while having treatment?
 - Should I change my diet or physical activity during or after treatment?
 - Are there any complementary therapies that might help me?
-

After treatment

- How often will I need check-ups after treatment?
 - Are there any long-term side effects or risks that I need to watch out for?
 - If 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, gallbladder, bowel, bladder and kidneys. Also known as the belly.

allogeneic stem cell transplant

A process that takes stem cells or tissues from one person and gives 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. Antibodies help protect against viruses, bacteria and other foreign substances.

antigen

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

autologous transplant

A process that takes stem cells or bone marrow from a person's own body and gives them back after high-dose chemotherapy.

B-cell

A type of lymphocyte (white blood cell) that makes antibodies to fight infection.

biopsy

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

disease. For lymphoma, a lymph node biopsy is common.

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, night sweats and weight loss, which are sometimes caused by lymphoma.

CAR T-cell therapy

Chimeric antigen receptor (CAR) 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.

checkpoint inhibitor

A drug that allows the immune system to pass "checkpoints" set up by the cancer to block the immune system.

chemotherapy

A cancer treatment that uses drugs to kill

cancer cells or slow their growth. May be given alone or with other treatments.

complete remission

When there is no evidence of active cancer. This may not mean that the cancer is cured.

core biopsy

A type of biopsy where a tissue sample is removed with a wide needle for examination under a microscope.

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 looked at under a microscope.

extranodal lymphoma

Advanced 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 commonly seen in certain types of cancer.

grade

A number that describes how similar cancer cells look to normal cells. Indicates how fast the tumour is growing. 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.

Hodgkin lymphoma

One of the two main groups of cancer of the lymphatic system. Also called 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

Drugs that use 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 (IV) infusion

A slow injection of a substance into a vein.

leukopenia

This is when there is a lower-than-normal number of leukocytes (white blood cells) in the blood.

lumbar puncture

When 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.

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 fluid

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

lymph nodes

Small glands found in groups throughout the body. They help protect the body against disease and infection. 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 2 main groups: non-Hodgkin lymphoma and Hodgkin lymphoma.

lymph vessels

Thin tubes that carry the clear fluid known as lymph all over 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.

non-Hodgkin lymphoma

Cancer of the lymphatic system. Also called non-Hodgkin's disease.

palliative treatment

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

peripheral T-cell lymphoma

A type of non-Hodgkin lymphoma of T-cells. 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 solution. This makes cancerous areas show up brighter on the scan.

platelets

One of the 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 therapy (radiotherapy)

The use of targeted 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.

red blood cells

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

Reed-Sternberg cell

Large, abnormal cells found in classical Hodgkin lymphoma.

refractory disease

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

relapse

The return of a disease after a period of improvement (remission). Also known as recurrence.

remission

When signs and symptoms of the cancer reduce or disappear. A partial remission is when there has been a reduction in symptoms, but some cancer is still present.

response

A decrease in the size of tumours because of treatment.

risk factor

A substance or condition that increases an individual's chances of developing a particular type of cancer.

screening trial

A trial that tests the best way to find cancer, especially in its earliest stages.

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 in the lymphatic system that makes lymphocytes, filters the blood and destroys old blood cells.

stage

The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

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 mostly used to reduce inflammation. Also called corticosteroids.

steroid therapy

Treatment with drugs to reduce inflammation, fatigue, pain and swelling.

targeted therapy

Drugs that attack specific features of cancer cells to stop the cancer growing and spreading. The 2 main types 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. It is a gland that helps make the white blood cells called T-cells.

thyroid

A butterfly-shaped gland at the base of the neck. It produces hormones to control the body's metabolism and calcium levels.

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 the 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
- cancervic.org.au/glossary

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3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia 2024*, AIHW, Canberra, viewed 10 June 2025, 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 your local Cancer Council.



Cancer Council

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

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

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our 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. accesshub.gov.au

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.*

