

Understanding Hodgkin Lymphoma

A guide for people with cancer, their families and friends



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

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

Editor: Nicole MacKee. Designer: Ali Wright. Printer: IVE Group.

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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 is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs.

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



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



Cancer Council NSW 153 Dowling Street, Woolloomooloo NSW 2011 ABN 51 116 463 846
Telephone 02 9334 1900 **Email** feedback@nswcc.org.au **Website** cancerCouncil.com.au

About this booklet

This booklet has been prepared to help you understand more about Hodgkin lymphoma in adults.

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

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 51 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 52). 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 Hodgkin lymphoma. It is based on clinical practice guidelines for 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



Tips

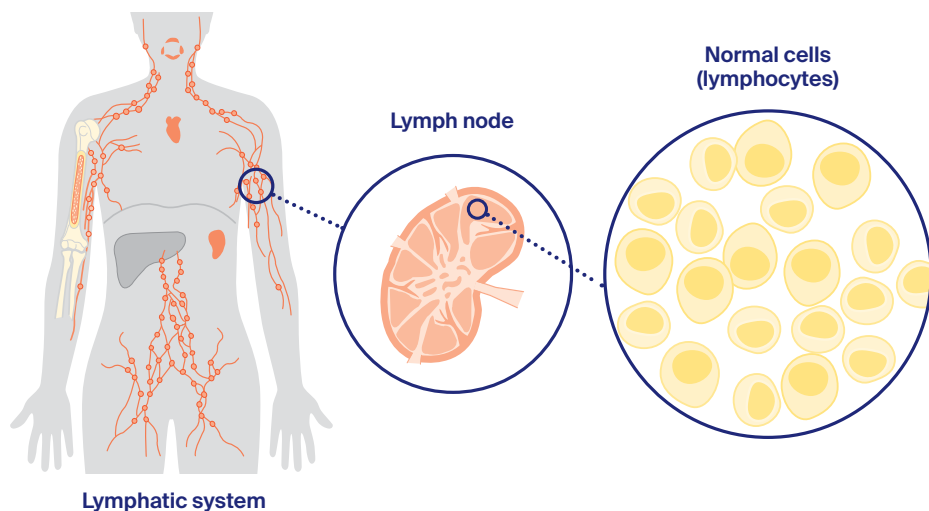
What is blood cancer?

Cancer is a disease of the cells, and cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Cancer develops when cells become abnormal and keep growing.

When a cancer begins in abnormal blood cells, it is known as a blood cancer. The 3 main groups of blood cancers are lymphoma, leukaemia and myeloma.

How lymphoma starts

Lymphoma usually starts in the lymph nodes.



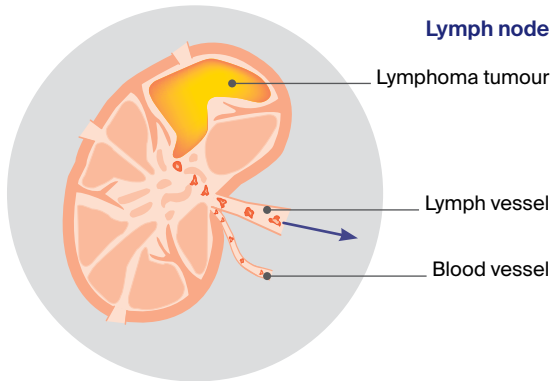
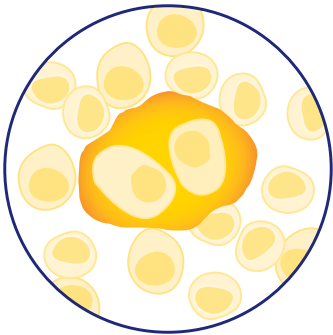
Lymphoma is cancer of the body's lymphatic system (see pages 6-7). It happens when abnormal white blood cells called lymphocytes grow uncontrollably and form a lump (tumour), usually in a lymph node. If these abnormal lymphocytes continue to build up, they can spread through the lymph and blood vessels to 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.

As the abnormal lymphocytes replace normal cells, the body's immune system becomes less able to resist and fight infections. Sometimes other types of cancer spread to the lymph nodes. This is not lymphoma. For example, breast cancer that spreads to the lymph nodes is still called breast cancer.

How lymphoma spreads

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

.....▶ **Abnormal cells
(Reed-Sternberg cells)**



The lymphatic system

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

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

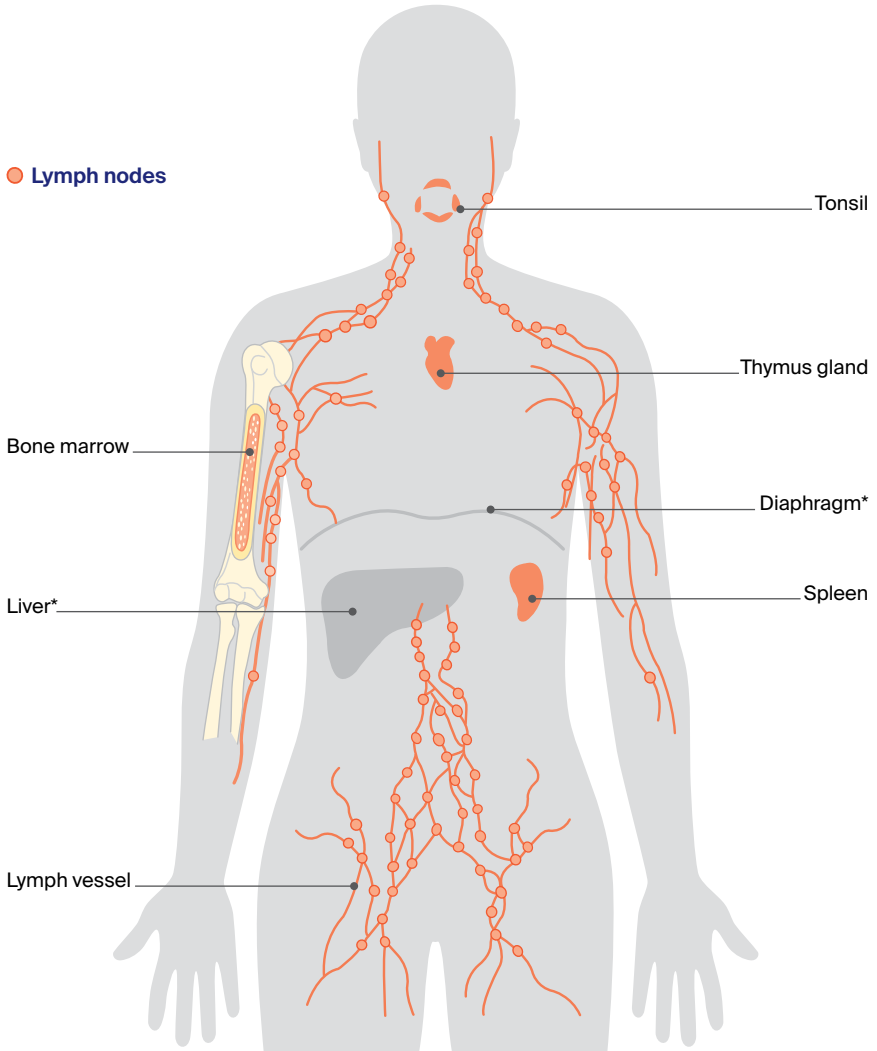
Lymph fluid – This clear fluid travels to and from the tissues in the body, carrying nutrients and taking away bacteria, viruses, abnormal cells and cell debris.

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

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

- bone marrow: produces blood cells (see pages 8-9)
- thymus gland: 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 inhaled or ingested germs
- digestive system: stores immune cells.

Parts of the lymphatic system



** Not part of the lymphatic system*

The role of blood cells

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

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

When germs become trapped in the lymph nodes, the nodes swell. Swollen lymph nodes are a sign that your body is fighting an infection. For example, the lymph nodes in your neck may swell when you have a sore throat. Swelling happens because the lymphocytes in the lymph nodes multiply to fight off the virus or bacteria that is causing the infection.

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

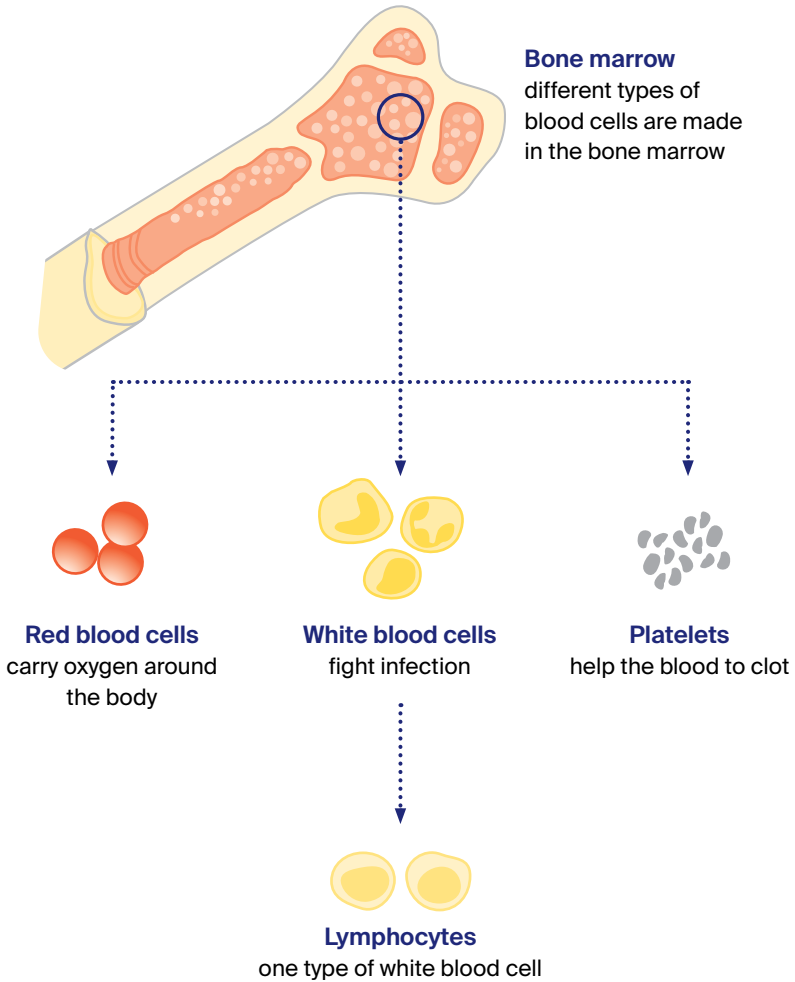
- A low level of white blood cells (neutropenia or lymphopenia) makes you more likely to get infections.
- A low level of red blood cells (anaemia) may make you look pale and feel tired, breathless and dizzy.
- A low level of platelets (thrombocytopenia) means you bruise or bleed easily.



For more information about lymphoma, visit Lymphoma Australia at lymphoma.org.au/lymphoma. For information about all types of blood cancer, visit leukaemia.org.au/blood-cancer.

Types of blood cells

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



Key questions

Q: What is Hodgkin lymphoma?

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

Hodgkin lymphoma is sometimes called Hodgkin's disease. The name Hodgkin comes from the doctor who first described this cancer. The disease usually starts in a lymph node at one or more places in the body. It can spread through the lymphatic system to other lymph tissue, particularly the spleen and bone marrow. Because the lymphatic system is a network throughout the body, Hodgkin lymphoma can appear in several parts of the body at the same time.

Sometimes, Hodgkin lymphoma spreads outside the lymphatic system to form a tumour in other organs, such as the spleen, liver or lung. This is known as extranodal disease.

Non-Hodgkin lymphoma

There are 2 main types of lymphoma: Hodgkin and non-Hodgkin. Non-Hodgkin lymphoma is more common. The 2 types look different when the diseased cells are examined under a microscope. A type of lymphocyte called a

Reed-Sternberg cell is seen in most cases of Hodgkin lymphoma, but it is not found in non-Hodgkin lymphoma. This booklet is only about Hodgkin lymphoma.

► See our *Understanding Non-Hodgkin Lymphoma* booklet.

What types are there?

There are 2 main types of Hodgkin lymphoma. Classical Hodgkin lymphoma is the most common type, and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) is rare. These types differ in how they look under the microscope, and how they grow and spread.

Classical Hodgkin lymphoma

- features large abnormal cells called Reed-Sternberg cells – these cells have a distinctive appearance when seen under a microscope
- occurs in 95% of people with Hodgkin lymphoma
- has 4 subtypes:
 - ▶ nodular sclerosis – 60–80% of cases; most common subtype
 - ▶ mixed cellularity – 25–30% of cases; often more advanced at diagnosis
 - ▶ lymphocyte-rich – 5% of cases
 - ▶ lymphocyte-depleted – fewer than 1% of cases
- usually managed with chemotherapy and radiation therapy (see pages 27–34 for more information)

NLPHL

- may also be called nodular lymphocyte-predominant B-cell lymphoma
- features abnormal cells – these cells are known as “popcorn cells” because of how they look
- occurs in fewer than 5% of people with Hodgkin lymphoma
- tends to grow more slowly and be diagnosed earlier than classical Hodgkin lymphoma and is managed differently
- may only need an operation to remove the lymph nodes, followed by regular check-ups to make sure the cancer hasn’t returned
- other treatments include chemotherapy, radiation therapy and a targeted therapy drug (see pages 27–34 and 40)
- in rare cases, can turn into non-Hodgkin lymphoma



This booklet is about Hodgkin lymphoma in adults. For information about Hodgkin lymphoma in children, see childrenscancer.canceraustralia.gov.au.

Q: How common is it?

A: Each year in Australia, about 760 people are diagnosed with Hodgkin lymphoma.³ Classical 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. The much rarer NLPHL mostly affects men in their 30s and 40s, and children.

Q: What are the symptoms?

A: Many people with Hodgkin lymphoma have few or mild symptoms, so it can be hard to diagnose. The most common symptom is a painless swelling in the neck, under the arm or in the groin. This swelling is caused by enlarged lymph nodes.

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

- fever with no obvious cause
- lots of sweating, especially at night
- losing weight without trying.

Other symptoms may include ongoing tiredness; rash or itching; unexplained cough; and shortness of breath. These symptoms can be caused by many other conditions, such as the flu or other viruses. Most people with these symptoms do not have Hodgkin lymphoma. However, if you have symptoms without any obvious cause, see your doctor.

Q: What are the risk factors?

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

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

Certain viruses – Infection with Epstein-Barr virus (the virus that causes glandular fever or infectious mononucleosis) or human immunodeficiency virus (HIV) increases the risk, but these infections are connected with only a small number of Hodgkin lymphoma cases. Most people with Epstein-Barr virus or HIV will not develop Hodgkin lymphoma.

Family history – Having a parent, brother or sister (first-degree relative) who has had Hodgkin lymphoma slightly increases a person's risk of developing it. However, this family history link is uncommon.

Many people with known risk factors don't develop Hodgkin lymphoma, and most people who do get it have no known risk factors. Hodgkin lymphoma is not contagious.



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

Q: Which health professionals will I see?

A: Your 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. The specialist will arrange further tests to work out if you have Hodgkin lymphoma.

Health professionals you may see

haematologist	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy and other drug therapies; conducts stem cell transplants
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
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, and provides care, information and support throughout treatment
clinical trials nurse	coordinates recruitment to clinical trials and acts as a link between you and the researchers if you join a clinical trial

If Hodgkin lymphoma is diagnosed, the specialist will consider treatment options. Usually 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 aspects of your care.

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
social worker	links you to support services and helps you with emotional, practical and financial issues
physiotherapist, occupational therapist	assist with physical and practical problems, including restoring movement and mobility and recommending aids and equipment
counsellor, psychologist	help you manage your emotional response to diagnosis and treatment
palliative care specialists and nurses	work closely with the GP and cancer specialists to help control symptoms and maintain quality of life

Diagnosis

If your GP suspects you have Hodgkin lymphoma, you will have a physical examination. They will feel the lymph nodes in your neck, underarms and groin for signs of swelling, and feel your abdomen for swollen organs. The doctor will also organise a biopsy and a blood test.

Biopsy

The most common way to diagnose and classify Hodgkin lymphoma is to remove some cells and tissue from an enlarged lymph node. This is called a biopsy and it is done in one of two ways.

Excision biopsy

- The whole lymph node or part of it is removed with surgery. This may be done as day surgery or you may be in hospital for a few days.
- Depending on the lymph node's location, you'll have a local or general anaesthetic.
- The wound will usually be closed with stitches.
- An excision biopsy helps ensure an accurate diagnosis. It is the preferred way to take a biopsy for Hodgkin 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 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 will be difficult to remove the lymph node or when Hodgkin lymphoma has returned after treatment.
- Depending on the pathology results, you may then need to have an excision biopsy.

Waiting for biopsy results

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

The results will probably 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. You can also call Cancer Council 13 11 20 for help during this time.

Further tests

If the biopsy of the enlarged lymph node shows that you have Hodgkin lymphoma, you will have several follow-up tests to find out whether the cancer has spread to other areas of your body. This is known as staging (see pages 21-22).

The following pages describe tests that are commonly used to help stage Hodgkin lymphoma. You will probably not need to have all of these tests - most people will have blood tests and a PET-CT or CT scan. Some tests may be repeated during or after treatment to see how well the treatment is working.

Because some types of treatment can affect the way your heart and lungs work, you may also have heart and lung tests before, during and after treatment.

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

Blood tests

Hodgkin lymphoma cannot be diagnosed with a blood test (when a sample of blood is removed from a vein in your arm using a needle). However, once Hodgkin lymphoma has been diagnosed, you will have regular blood tests to check how the treatment is affecting the levels of blood cells in your body.

A test known as a full blood count (FBC) estimates your total number of red blood cells, white blood cells and platelets. Your results will be compared against the normal ranges, which are known as reference ranges or intervals. Reference ranges depend on many factors, including your age and gender, and the test method and laboratory. Talk to your treatment team about the reference ranges they are using for you.

Blood is also taken to see how well your bone marrow, kidneys and liver are working. If you are likely to have treatment that will affect your immune system, the blood sample will be checked for hepatitis and HIV.

In the hours leading up to your blood test, drink plenty of water as this can help your veins to show up and make the procedure easier.

Imaging tests

You will usually have at least one of the imaging tests or scans described below.

PET-CT scan – This specialised test combines a positron emission tomography (PET) scan with a computerised tomography (CT) scan to produce a 3-dimensional colour image. It is available at many major hospitals, and can show whether the lymphoma has spread to the bone

marrow, lymph nodes or other organs. A PET-CT scan can also be used later to check how the lymphoma has responded to treatment.

You will be asked not to eat or drink anything for several hours before the scan. The scanners look like a large box with a hole in the middle, and you will need to lie on a table that moves in and out of the scanner. Let your doctor know if you are claustrophobic, as the scanner is a confined space.

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

You will be asked to sit quietly for 30–90 minutes while the glucose moves around your body, then the PET scan itself will take about 30 minutes. The radiation absorbed into your body during a PET scan is generally not harmful and will leave your body within a few hours.

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

CT scan – This scan uses x-rays and a computer to create a detailed picture of an area inside the body. If a PET-CT scan is not available, you will have a CT scan of your neck, chest and abdomen to help work out how far the Hodgkin lymphoma has spread.



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

Before a CT scan, you may have a special dye called contrast injected into a vein to help make the pictures clearer. It might make you feel hot all over and leave a strange taste in your mouth for a few minutes.

The CT scanner is large and round like a doughnut. You will lie on a table that moves in and out of the scanner. The scan is painless and the whole procedure takes around 30–45 minutes. Most people are able to go home as soon as the scan is over.

Ultrasound – This test is most commonly used to help find swollen lymph nodes or other lumps in the body, and to guide the needle to the correct lymph node during a core biopsy (see page 16).

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

Bone marrow biopsy

Very rarely, you may need a biopsy to check whether the bone marrow contains cancer cells. For this type of biopsy, you will lie on your side while a local anaesthetic is injected into your pelvis (hip). You may also be offered medicine to help you relax (light sedation). A bone marrow biopsy is done in 2 steps:

Bone marrow aspiration – First, the doctor uses a needle to remove a small sample of fluid from the bone marrow in your hip.

Bone marrow trephine – Next, the doctor uses another needle to take a matchstick-width sample of both bone and bone marrow tissue.

You could feel some pressure or discomfort during the biopsy. If you feel uncomfortable after the biopsy, talk to a member of your health care team about pain relief options.

Staging Hodgkin lymphoma

Staging is a way of describing how far Hodgkin lymphoma has spread throughout the body. Using the tests explained on pages 16–20, your doctor can work out the stage of cancer and recommend treatment.

Stages 1 and 2 are considered early-stage lymphoma, and stages 3 and 4 are considered advanced-stage lymphoma (see table below).

Each stage is also given a letter (A or B) based on whether you have specific symptoms:

- The letter A means you have none of the B symptoms (listed below).
- The letter B means you have fever, night sweats and/or unexplained weight loss (typical lymphoma symptoms).

Hodgkin lymphoma stages

stage 1	one lymph node area is affected, either above or below the diaphragm
stage 2	two or more lymph node areas are affected on the same side of the diaphragm
stage 3	at least one lymph node area above and at least one lymph node area below the diaphragm are affected
stage 4	lymphoma is in multiple lymph nodes and has spread to other parts of the body (e.g. bones, lungs, liver)

Risk categories

Your doctor will consider the stage (see previous page) along with the results of blood tests and imaging scans to work out how the 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 include:

- many affected lymph nodes
- larger lymph nodes (may be called bulky disease)
- inflammation in the blood
- the presence of B symptoms (see previous page).

Advanced Hodgkin lymphoma is generally categorised as high risk.

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

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 in an individual person. Instead, your doctor can

give you an idea about the common issues that affect people with your type of Hodgkin lymphoma.

To work out your prognosis, your doctor will consider:

- your test results
- the type of Hodgkin lymphoma you have
- the stage and risk category
- how well the Hodgkin lymphoma responds to treatment (you will have tests throughout your treatment that show how well the treatment is working)
- your age, fitness and medical history.

Hodgkin lymphoma usually responds well to treatment, and most people who are treated for Hodgkin lymphoma (including advanced disease) go into remission. This means the symptoms of Hodgkin lymphoma disappear and the doctor can't find any sign of the disease during a physical examination or on imaging tests.

During remission, you will need regular check-ups to ensure that you are still healthy, and the lymphoma hasn't returned.

In a small number of cases, Hodgkin lymphoma may not respond to the initial treatment, which is known as refractory disease, or it may come back (relapse or recur) after remission. See pages 37–41 for information about treatment for refractory or relapsed disease.

Key points about diagnosing Hodgkin lymphoma

Initial tests

Your GP will do a physical examination to check for swelling in your lymph nodes, neck, underarms, groin and the organs in your abdomen.

Diagnostic tests

A biopsy of a swollen lymph node is the most common way to diagnose Hodgkin lymphoma:

- All or part of the lymph node will be removed and the cells will be examined under a microscope.
 - The biopsy is done as either a core biopsy or excision biopsy.
 - Sometimes, a biopsy will need to be repeated to gather enough cells to make a diagnosis.
-

Other tests

Other tests provide more information to help plan your treatment:

- Blood tests check the levels of different types of blood cells and how well your bone marrow, kidneys and liver are working.
 - Staging tests work out how far the Hodgkin lymphoma has spread through the body. They may include a PET-CT or CT scan; ultrasound; and bone marrow biopsy.
-

Prognosis

- Your doctor may talk to you about your prognosis or expected outcome.
 - Your prognosis will depend on several factors, including the stage and risk category of the Hodgkin lymphoma.
 - After initial treatment, most people with Hodgkin lymphoma go into remission, when tests show no evidence of the disease.
-



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

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

Record the details – When your doctor first 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 51 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

The aim of treatment for Hodgkin lymphoma is to control the cancer so it goes into remission. This is when the symptoms and signs of cancer reduce or disappear. The most important factors in planning treatment are your stage and risk category. The treatment recommended will also depend on your age, symptoms and general health.

Chemotherapy and radiation therapy are the main treatments for Hodgkin lymphoma. These are often combined to improve outcomes.

A stem cell transplant (see pages 37–39) may be offered if Hodgkin lymphoma does not fully respond to the first treatment or returns after remission. Targeted therapy and immunotherapy drugs (see pages 40–41) may be suitable for some people with advanced Hodgkin lymphoma.

“On the first day of my treatment, I ate plain foods and reduced caffeine. I wrote down my drug regime, so I was clear on what to take and when.” AMY

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. There are guidelines (protocols) that set out how much and how often to have particular chemotherapy drugs, depending on the stage of the lymphoma. You can find information about chemotherapy protocols at eviq.org.au, although your specialist may need to tailor the plan to your individual situation. Your treatment team will give you information about your schedule.

Having chemotherapy

Some chemotherapy drugs are taken as tablets, but most are given by drip into a vein (intravenous infusion). Intravenous infusions may be given in different ways, depending on how often you need chemotherapy, how long it takes to give each dose, and how long the device needs to stay in place. Some people have a small plastic tube called a cannula inserted into an arm or hand at each visit. Others have a central venous access device (CVAD), a tube that remains in a vein throughout the course of treatment. Your doctor or nurse will let you know if you need a cannula or CVAD to have your treatment.

There are different types of CVADs, including:

- central lines - inserted into the chest or neck
- Hickman lines - inserted into the chest
- PICC (peripherally inserted central catheter) line - inserted into the arm
- port-a-caths (ports) - a small device inserted under the skin of the chest or arm.

In most cases, you will have chemotherapy at the hospital or treatment centre as an outpatient and won't need to stay overnight.

For Hodgkin lymphoma, you will have several chemotherapy drugs, usually given in cycles spread over 3–6 months. Each cycle takes 2–4 weeks and includes rest days. Sometimes after the first 2 cycles, you may have a PET-CT scan to check how the Hodgkin lymphoma has responded. This is known as restaging, and it helps your team work out whether to adjust the chemotherapy you are given.

You will also have regular blood tests throughout treatment. If your white blood cell count is low (called neutropenia or lymphopenia), you may be given injections of granulocyte-colony stimulating factor (G-CSF).

G-CSF is a substance that helps to increase your white cell count and protect you from infection. Sometimes, you may need to delay your chemotherapy until your white cell count improves.

Side effects of chemotherapy

Chemotherapy drugs work mainly on fast-growing cells, such as lymphoma cells. However, the drugs may also damage other types of fast-growing cells, such as hair follicles, blood cells, and cells inside the mouth or bowel. This can cause side effects. Some people may have few side effects, while others may have several. Most side effects are temporary and can be managed, however, fatigue can build up over time and become worse with each treatment cycle.

Before treatment, your health care team will tell you what side effects to expect and how to manage them. It is important to discuss any side effects of treatment with your doctor or nurse. They may need to closely monitor the problem or change your treatment. Some of the common side effects are described on the next 2 pages.

Fertility and cancer treatment

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, and if you have periods, they may become irregular or stop permanently (menopause).

Most people treated for Hodgkin 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.

Common side effects of chemotherapy

Different chemotherapy drugs can have different side effects, and everyone reacts to chemotherapy differently. For more information about

Fatigue



Severe tiredness and lack of energy (fatigue) may make you feel weak and exhausted. These feelings 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). This can be treated with blood transfusions. Otherwise, keeping active and exercising can help you feel less fatigued.

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

Nerve and muscle 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.

Increased risk of infections



Chemotherapy reduces your white blood cell level (neutropenia and lymphopenia), making it harder for your body to fight infections. See page 32 for details on reducing your risk of infection.

Thinking and memory changes

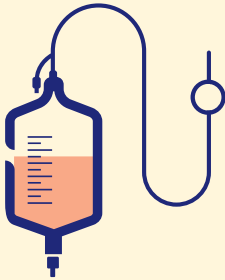


Some people say they have difficulty concentrating, focusing and remembering things after they have had chemotherapy. These problems usually improve with time, but some people experience issues for months or years.

► See our *Changes in Thinking and Memory* fact sheet.

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

Bleeding or bruising



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

Dental problems



If your platelet count falls, your gums may bleed more easily. You may also develop mouth sores or infections. Use a soft toothbrush and see your dentist for regular check-ups. Check with your treatment team before having major dental work.

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

Hair thinning or hair loss



You may lose some hair from your head, eyebrows and eyelashes. Your hair will grow back after treatment, but it may look or feel different. 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 *Hair Loss* fact sheet.

Nausea and vomiting



Before each chemotherapy session, you will usually be given anti-nausea medicines to stop you feeling sick or vomiting, as well as medicines to take at home. You may take several different types of medicine, and these usually work well. Talk to a dietitian about adjusting what you eat.

► 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.

How 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 or 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 people you live with if they are unwell
- try to avoid very crowded places, such as public transport in peak hour, where possible
- prepare and store food properly to avoid foodborne illnesses and food poisoning
- wash your hands with soap and water before preparing food and eating, and after using the toilet
- eat freshly cooked foods and avoid raw foods (fish, seafood, meat and eggs) and soft cheeses
- wash fruits and vegetables before eating.

When to seek medical help

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

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

Steroids

Steroids are made naturally in the body. They can also be produced artificially and used as a drug to reduce inflammation (redness, swelling and/or pain). The steroids usually used for Hodgkin lymphoma are prednisone or prednisolone. These are known as corticosteroids.

You may be given steroids to increase the effect of the chemotherapy, help destroy the lymphoma, and treat any nausea and vomiting caused by chemotherapy. Steroids may also be used with targeted therapy or immunotherapy (see pages 40–41). Steroids are usually taken as tablets, but can also be given into a vein (intravenously).

Side effects of steroids

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

If you need to take steroids for several months, this may cause a build-up of fluid in the body and face (fluid retention), high blood pressure, and an increase in glucose levels, which may lead to diabetes in some people. You may also be more likely to get infections and, over time, your skin, muscles and bones may weaken.

Radiation therapy

Radiation therapy (also known as radiotherapy) uses radiation to kill or damage cancer cells so they cannot grow, multiply or spread. You may have radiation therapy after chemotherapy. The type of radiation therapy used to treat Hodgkin lymphoma is called external beam radiation therapy (EBRT). It is delivered using a machine called a linear accelerator, which produces high-energy x-rays that target cancer cells.

Planning for radiation therapy

About 3 weeks before you start your treatment, your radiation oncologist will use the results of your imaging scans to help work out the lymph node areas to target with radiation. You will have a planning session with your radiation oncologist, and have another CT scan. This session will take 1-2 hours and will help your treatment team to precisely target the cancer while avoiding healthy cells.

Having radiation therapy

Radiation therapy usually starts about a month after your last chemotherapy cycle. You will be in the treatment room for about 15-45 minutes. The radiation therapist will make sure you are in exactly the same position during each treatment. The actual treatment takes only 1-2 minutes, and you will not be able to see or feel the radiation. Treatments are delivered daily from Monday to Friday over 2-4 weeks.

Side effects of radiation therapy

Radiation doses used today are lower and more targeted than in the past, so there are fewer side effects. The most common side effect of radiation therapy is tiredness. Talk to your treatment team about suitable exercise during radiation therapy - improving fitness can help reduce tiredness. Other side effects will depend on the part of the body being treated, for example, radiation therapy to the abdomen may cause an upset stomach and diarrhoea. Treatment can also lead to skin changes such as red, dry and itchy skin at the treatment area.

Side effects can build up towards the end of the course of treatment, but most will be temporary. You will have regular reviews with the radiation oncologist or other team members to monitor your progress and support you. Talk to your treatment team about any side effects that concern you.

► See our *Understanding Radiation Therapy* booklet.

Late effects of treatments

Some side effects from chemotherapy or radiation therapy may not show up until months or years after treatment. These are called late effects.

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

If any symptoms do appear, even many years after treatment, ask your GP whether they could be related to the treatment you had for Hodgkin lymphoma.

When treatment finishes, ask your doctors for details of the chemotherapy and radiation therapy you had so you have this on hand if any late effects do occur.

Heart problems – Chemotherapy can increase the risk of heart disease, and radiation therapy to the chest area can lead to heart disease.

Lung problems – Some types of chemotherapy can increase the risk of long-term lung problems.

Talk to your doctor if you notice lung symptoms, such as shortness of breath.

Second cancer – In some cases, there may be an increased risk of developing another cancer near the area where radiation therapy was given. People treated with some chemotherapy drugs may also have a higher risk of developing a second cancer later in life.

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 29).

Osteoporosis – Reaching menopause early may increase the risk of osteoporosis. This is when bones become weaker and thinner and can lead to bone pain and fractures.



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 BEACOPP – a combination of chemotherapy drugs – which 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.

Stem cell transplant

If Hodgkin lymphoma comes back (relapses or recurs) or doesn't respond completely to initial treatment (refractory disease), you may need a stem cell transplant. However, stem cell transplants are used less often now than in the past.

A stem cell transplant is a demanding treatment and is not suitable for everyone, especially people with other health problems. The entire procedure, including recovery, can take months.

Before the stem cell transplant, you will have a high dose of chemotherapy. You will need to repeat tests, such as PET-CT scans and blood tests, throughout the treatment.

Stem cells are unspecialised blood cells that can develop into white or red blood cells or platelets. For a transplant, stem cells can be taken from the bloodstream (peripheral blood stem cell transplant), bone marrow (bone marrow transplant) or, rarely, umbilical cord blood (cord blood transplant). There are 2 main types of stem cell transplants.

Autologous transplant – when your stem cells are removed from your blood and later put back (infused) into your body. This is the most common type of transplant used to treat Hodgkin lymphoma. An autologous transplant is done in several steps (see the next 2 pages).

Allogeneic transplant – when the stem cells are collected from another person (a donor). In this type of transplant, donor blood stem cells are used to rebuild the immune system and prevent relapse. There is a risk of graft-versus-host disease (when the immune cells in the transplanted tissue attack the person's cells) with this type of transplant, and it is not often used to treat Hodgkin lymphoma.

Steps in an autologous stem cell transplant

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

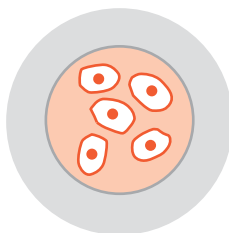
1. Stem cells stimulated



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

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

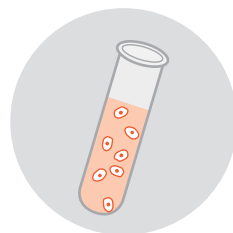
2. Stem cells collected



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

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

3. Stem cells preserved

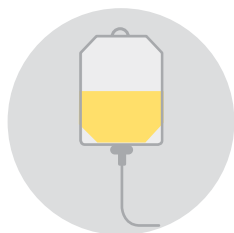


The stem cells are frozen using liquid nitrogen. This is known as cryopreservation.

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

More detailed information about stem cell transplants is available from the Leukaemia Foundation, phone 1800 620 420 or visit leukaemia.org.au.

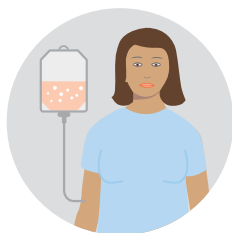
4. High-dose chemotherapy



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

Side effects will be similar to those of standard chemotherapy but can be more intense. They may include nausea, diarrhoea, mouth sores, flu-like symptoms and high risk of infections (see page 32).

5. Stem cells transplanted



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

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

6. Engraftment



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

While the stem cells engraft, you're at risk of infection. In most cases, you will stay in hospital for 1–3 weeks until your blood counts have returned to safe levels and you're well enough to go home.

Once home, you'll need check-ups every week or so. Over time, you'll need check-ups less often.

Targeted therapy

Targeted therapy drugs attack specific features of cancer cells to stop the cancer growing or to reduce its size. A drug called brentuximab vedotin combines a targeted therapy drug with a chemotherapy drug.

Brentuximab vedotin may be used for some people with relapsed or refractory Hodgkin lymphoma. It is usually given through a drip inserted into a vein in the arm (intravenous infusion) every 3 weeks.

Rituximab may be used to treat people with the less common subtype nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL, also called nodular lymphocyte-predominant B-cell lymphoma). NLPHL cells make a protein called CD20, and rituximab targets this protein. Rituximab is given into a vein through a drip (intravenous infusion).

Clinical trials (see page 26) are testing other targeted therapy drugs for Hodgkin lymphoma. Ask your doctor about the latest developments.

Side effects of targeted therapy

The side effects of brentuximab vedotin may include nausea, fatigue, increased risk of infection and bleeding, and numbness, tingling and sometimes pain in the hands and feet (peripheral neuropathy). Common side effects of rituximab include headaches, fever and skin rash.

Immunotherapy

This type of drug therapy uses the body's own immune system to fight cancer. An immunotherapy drug called pembrolizumab is available for some people with relapsed or refractory Hodgkin lymphoma. It is usually given as an intravenous infusion every 3 weeks. Pembrolizumab can be used alone or combined with chemotherapy.

Other immunotherapy drugs for Hodgkin lymphoma may be available through clinical trials (see page 26). Ask your doctor about the latest developments in immunotherapy for Hodgkin lymphoma.

Side effects of immunotherapy

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

- ▶ See our *Understanding Targeted Therapy* and *Understanding Immunotherapy* fact sheets or listen to our “New Cancer Treatments” podcast episode.

Palliative treatment

Palliative treatment helps to improve people’s quality of life by managing the symptoms of lymphoma without trying to cure the disease. Many people think that palliative treatment is for people at the end of their life; however, it can help people at any stage.

As well as slowing the spread of Hodgkin lymphoma, palliative treatment can relieve pain and help manage other symptoms. Treatment may include radiation therapy, chemotherapy or other medicines. If you are experiencing ongoing symptoms, you can 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.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets or listen to our podcast about advanced cancer.

Key points about treating Hodgkin lymphoma

Treatment options

- Treatment is based mainly on the stage and risk category of the Hodgkin lymphoma.
 - Other factors include your age, symptoms and general health.
-

Main treatments

- Chemotherapy uses drugs to kill cancer cells or slow their growth.
 - 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. They may also be used with targeted therapy and immunotherapy (see below).
 - Radiation therapy uses targeted radiation to kill cancer cells or injure them so they cannot multiply.
 - Side effects of radiation therapy depend on the area of your body that is treated.
-

Further treatments

- A stem cell transplant may be an option if the Hodgkin lymphoma returns (relapses) or does not respond to other treatments (refractory disease). Most people who have a stem cell transplant use their own stem cells (autologous stem cell transplant).
 - Some people with relapsed or refractory Hodgkin lymphoma may be able to have targeted therapy or immunotherapy drugs.
 - Clinical trials often play an important role in treatment.
 - Palliative treatment can be used at any stage of advanced cancer to control symptoms and stop the lymphoma from spreading further.
-

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 appetite 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.

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

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

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

▶ See our *Fertility and Cancer* booklet.

Life after treatment

For most people, the lymphoma experience doesn't end on the last day of treatment. Life after lymphoma treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the lymphoma 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.



People who have received treatment for Hodgkin lymphoma are at an increased risk of heart and lung problems – talk to your doctor about lifestyle changes you can make to reduce your risk.

Follow-up appointments

After treatment ends, 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. During these check-ups, you will usually have a physical examination and you may have blood tests, x-rays or scans. You will also be able to discuss how you're feeling and mention any concerns you may have.

Your specialist may want to see you 3–4 times a year for the first couple of years. This will gradually decrease to twice a year. Your specialist will talk to you about the best follow-up schedule for your situation.

When a follow-up appointment or test is coming up, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

What if lymphoma returns?

For some people, Hodgkin lymphoma does come back after treatment (relapse or recurrence). This is why regular check-ups are important.

Hodgkin lymphoma that has relapsed can still be treated, usually with a different type of chemotherapy. You may also be offered radiation therapy. Some people with relapsed Hodgkin lymphoma have a stem cell transplant (see pages 37–39) to increase the chance of remission. Most people who have a relapse will go into remission again.

Caring for someone with cancer

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.

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 creates 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 the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

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

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20



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

Information resources



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

Legal and financial support



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

Practical help



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

Peer support services



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

Useful websites

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

Australian

Cancer Council NSW	cancercouncil.com.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Arrow Bone Marrow Transplant Foundation	arrow.org.au
Australasian Leukaemia & Lymphoma Group	allg.org.au
Australian Bone Marrow Donor Registry	abmdr.org.au
Australian Cancer Trials	australiancancertrials.gov.au
Cancer Australia	canceraustralia.gov.au
Cancer Institute NSW	cancer.nsw.gov.au
eviQ Cancer Treatments Online	eviq.org.au
Leukaemia Foundation	leukaemia.org.au
Lymphoma Australia	lymphoma.org.au
Services Australia (including Centrelink and Medicare)	servicesaustralia.gov.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Lymphoma Research Foundation (US)	lymphoma.org
Macmillan Cancer Support (UK)	macmillan.org.uk

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 Hodgkin lymphoma do I have? What stage/risk category is it?
 - Are the latest tests and treatments for lymphoma available in this hospital?
 - Will a multidisciplinary team be involved in my diagnosis and treatment?
 - Are there clinical guidelines for this type of lymphoma?
-

Treatment

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

Side effects

- What are the risks and possible side effects of each treatment?
 - Will the treatment affect my sex life and fertility?
 - Will I lose my hair?
 - 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 the lymphoma returns, how will I know? What treatments could I have?
-

Glossary

abdomen

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys. Also known as the belly.

allogeneic transplant

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

anaemia

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

anaesthetic

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

apheresis

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

autologous transplant

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

biopsy

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

blood count

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

bone marrow

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.

chemotherapy

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

classical Hodgkin lymphoma

The most common type of Hodgkin lymphoma. It has 4 subtypes: nodular sclerosis, mixed cellularity, lymphocyte-rich and lymphocyte-depleted.

core biopsy

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

CT scan

Computerised tomography scan. It uses x-rays to create detailed pictures of the body.

cycle

A period of chemotherapy treatment that is repeated on a regular schedule with periods of rest in between.

diaphragm

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

engraftment

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

Epstein-Barr virus

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

excision biopsy

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

extranodal lymphoma

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

fertility

The ability to conceive a child.

granulocyte-colony stimulating factor (G-CSF)

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

growth factor

A protein that stimulates the development and growth of cells.

haematologist

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

HIV (human immunodeficiency virus)

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

Hodgkin lymphoma

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

immune system

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

immunotherapy

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

intravenous infusion

A slow injection of a substance into a vein.

liver

A large organ in the top right side of the abdomen. The liver plays an important role in cleaning the blood and helping digestion.

lymphatic system

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat, and produces immune cells.

lymph fluid

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

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They collect and destroy bacteria and viruses. Also called lymph glands.

lymphocyte

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

lymphoma

A type of blood cancer affecting the lymphatic system. There are 2 main types: Hodgkin lymphoma and non-Hodgkin lymphoma.

lymphopenia

A low level of lymphocytes (a type of white blood cell). Lymphopenia can make you more prone to infections.

lymph vessels

Thin tubes that carry the clear fluid known as lymph. They are found throughout the body.

MRI scan

Magnetic resonance imaging scan. A scan that uses magnetic fields and radio waves to take detailed, cross-sectional pictures of the body.

neutropenia

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

nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

An uncommon type of Hodgkin lymphoma. May also be called nodular lymphocyte predominant B-cell lymphoma.

non-Hodgkin lymphoma

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

palliative treatment

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

peripheral neuropathy

Weakness, numbness, tingling or pain, usually in the hands and feet, caused by damage to the nerves that are located away from the brain and spinal cord (peripheral nerves). A possible side effect of chemotherapy.

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.

port-a-cath (port)

A type of central venous access device surgically inserted under the skin of the chest or the arm. A tube called a catheter connects the port to a vein so fluids can be passed into the body.

prognosis

The expected outcome of a particular person's disease.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Also known as radiotherapy.

red blood cells

One of the 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. Sometimes known as residual disease.

relapse

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

remission

When the signs and symptoms of the cancer reduce or disappear. A partial remission is when there has been a significant reduction in symptoms but some cancer is still present. A complete remission is when there is no evidence of active cancer.

spleen

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

stem cells

Unspecialised 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, then replaced by healthy stem cells.

steroids

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

systemic treatment

Treatment that reaches cancer cells throughout the body. Includes chemotherapy, immunotherapy and targeted therapy.

targeted therapy

Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

thrombocytopenia

A low level of platelets. It can be a side effect of chemotherapy and makes you more prone to bleeding and bruising.

thymus gland

A part of the lymphatic system. It helps make the white blood cells called T-cells.

tissue

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

tonsils

Small masses of lymphatic tissue at the back of the mouth that help to fight infection.

transfusion

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

tumour

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

ultrasound

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

white blood cells

One of the three main types of cells found in the blood. White blood cells help fight infection. Lymphocytes are a type of white blood cell.

Can't find a word here?

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

References

1. DA Eichenauer et al., "Hodgkin lymphoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 29 (supplement 4), 2018, pp. iv19–iv29.
2. National Comprehensive Cancer Network (US), *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Hodgkin Lymphoma*, Version 2.2023, available from [nccn.org](https://www.nccn.org).
3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia 2022*, AIHW, Canberra, viewed 28 March 2023, available from aihw.gov.au/reports/cancer/cancer-data-in-australia.



How you can help

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

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

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

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

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

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

To find out more about how you, your family and friends can help, please call Cancer Council NSW on 02 9334 1900.



Cancer Council

13 11 20

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

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

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

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



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



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. 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.*

