



# Understanding Hodgkin Lymphoma

A guide for people with cancer,  
their families and friends

Cancer  
information

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## Understanding Hodgkin Lymphoma

A guide for people with cancer, their families and friends

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*Understanding Hodgkin Lymphoma* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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

### Note to reader

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

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

### Cancer Council NSW

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



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This booklet was printed with support from the Dry July Foundation.

# 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.<sup>1</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit our website at [cancercouncil.com.au](http://cancercouncil.com.au).



**Cancer  
Council**  
**13 11 20**

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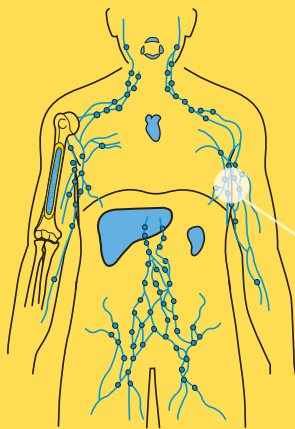
# What is blood cancer?

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

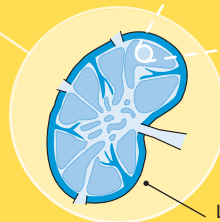
## How lymphoma starts

Lymphoma usually begins in a lymph node.

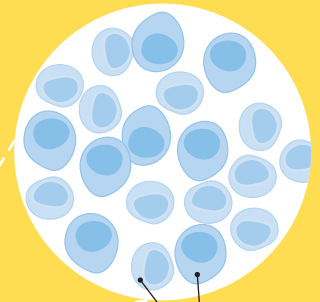


Lymphatic system

**Normal lymphocytes**  
Lymph nodes contain white blood cells called lymphocytes.



Lymph node



Normal lymphocytes

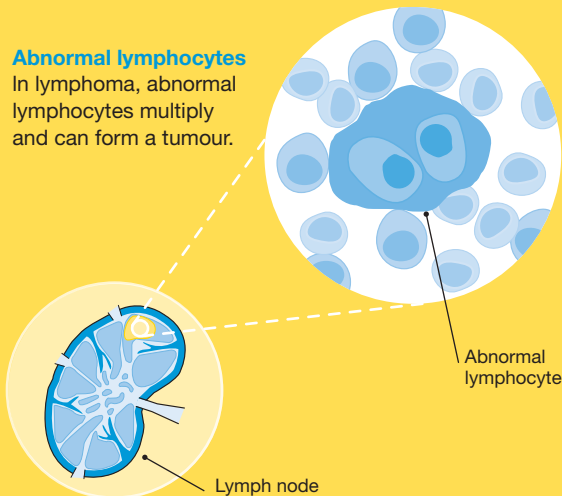
(tumour), usually in a lymph node. If these abnormal lymphocytes continue to build up, they can spread through the lymph vessels to form a tumour in another part of the lymphatic system. Occasionally, lymphoma travels through the bloodstream to form a tumour in an organ outside the lymphatic system,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

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

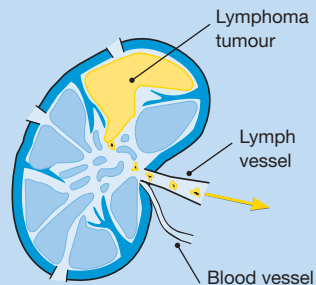
### Abnormal lymphocytes

In lymphoma, abnormal lymphocytes multiply and can form a tumour.



### How lymphoma spreads

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





# The lymphatic system

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. It is made up of a network of vessels, tissues and organs:

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

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

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

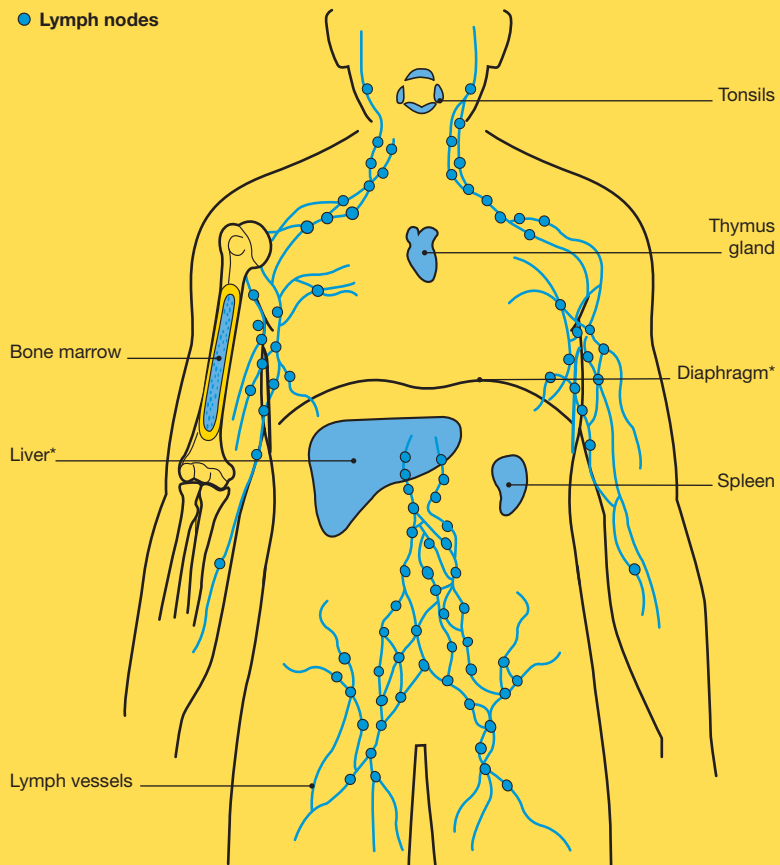
**Other lymph tissue** – As well as lymph nodes, lymph tissue is found in other parts of the body:

- bone marrow – produces blood cells (see pages 8–9)
- thymus gland – helps produce white blood cells
- spleen – stores white blood cells, filters waste products from the blood, and destroys old blood cells, abnormal cells and bacteria
- tonsils – trap inhaled or ingested germs
- some lymph tissue in the digestive system.



## Anatomy of the lymphatic system

● Lymph nodes



\* Not part of the lymphatic system

## The role of blood cells

The bone marrow is the soft, spongy material inside bones. It produces stem cells, which are unspecialised blood cells that usually grow into one of three main types of blood cells: red blood cells, white blood cells and platelets. Each type of blood cell has a specific function (see 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 become swollen, which is 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. The swelling happens because the lymphocytes in the lymph nodes multiply to fight off the virus or bacteria that is causing the infection.

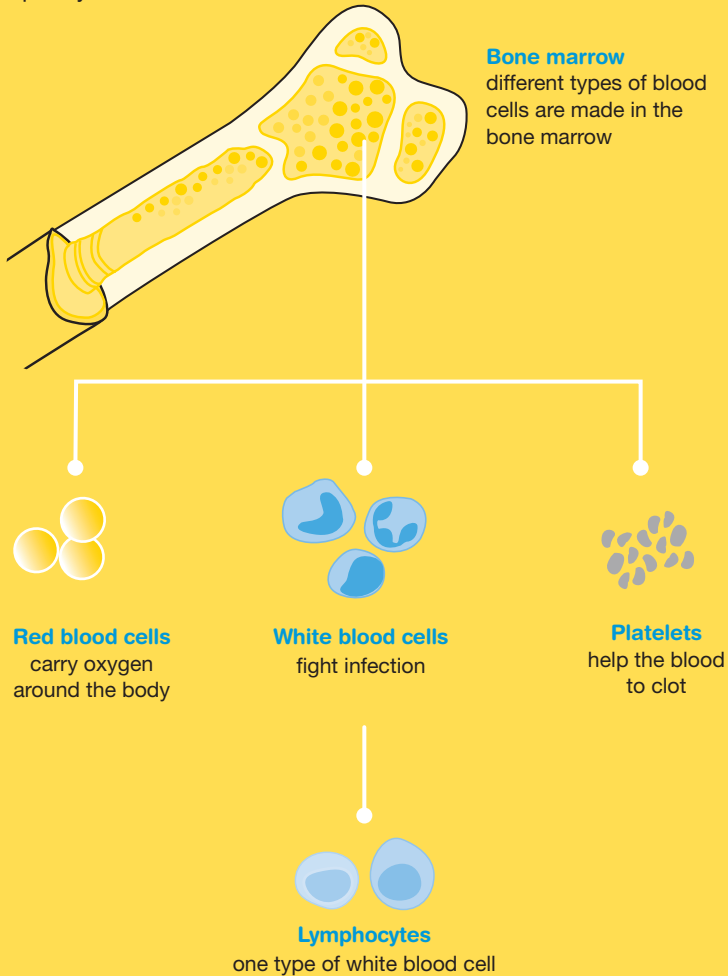
Diseases such as lymphoma or treatments such as chemotherapy can lower the number of blood cells in the body, and this can cause particular symptoms:

- Low levels of white blood cells can cause neutropenia, which makes you more likely to get infections.
- Low levels of red blood cells can cause anaemia, which may make you look pale and feel tired, breathless and dizzy.
- Low levels of platelets can cause thrombocytopenia, which means you bruise or bleed easily.

For more information about the role of blood cells and all types of blood cancers, you can visit the Leukaemia Foundation at [leukaemia.org.au/disease-information](http://leukaemia.org.au/disease-information).

## Types of blood cells

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





## Key questions

### Q: What is Hodgkin lymphoma?

**A:** Hodgkin lymphoma is a blood cancer that begins in the white blood cells called lymphocytes. 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, and is often first noticed in the neck. It can spread through the lymphatic system from one group of lymph nodes to another, and to other lymph tissue, particularly the spleen and bone marrow. Sometimes Hodgkin lymphoma appears in several parts of the body at the same time.

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

### Non-Hodgkin lymphoma

There are two main types of lymphoma: Hodgkin lymphoma and non-Hodgkin lymphoma. Non-Hodgkin lymphoma is more common. The two types look different when the diseased cells are examined under a microscope. A type of lymphocyte called a Reed-Sternberg cell is seen in most cases of Hodgkin lymphoma, but it is not found in non-Hodgkin lymphoma. This booklet is only about Hodgkin lymphoma. For a free booklet on non-Hodgkin lymphoma, call Cancer Council **13 11 20** or find it online at [cancercouncil.com.au](http://cancercouncil.com.au).

## Q: What types are there?

**A:** Classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) are the two main types of Hodgkin lymphoma. They differ in how they look under the microscope, and how they grow and spread.

### Classical Hodgkin lymphoma

- features large abnormal cells known as Reed-Sternberg cells, which have a distinctive appearance when seen under a microscope
- makes up about 95% of all cases of Hodgkin lymphoma
- has four subtypes:
  - **nodular sclerosis** – most common subtype (60–80% of cases)
  - **mixed cellularity** – 25–30% of cases, often more advanced at diagnosis
  - **lymphocyte-rich** – 5% of cases
  - **lymphocyte-depleted** – fewer than 5% of cases
- usually managed with chemotherapy and radiation therapy (see pages 27–34 for more information)

### NLPHL

- features abnormal cells 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 (known as “watch and wait”)
- other treatments include chemotherapy, radiation therapy and targeted therapy (see pages 27–41)
- in rare cases, can turn into non-Hodgkin lymphoma



This booklet is about Hodgkin lymphoma in adults. For Hodgkin lymphoma in children, see [childrenscancer.cancer australia.gov.au](http://childrenscancer.cancer australia.gov.au).

## Q: How common is it?

**A:** Each year in Australia, about 647 people are diagnosed with Hodgkin lymphoma.<sup>2</sup> Classical Hodgkin lymphoma most commonly develops in younger people aged 15–29 and older people aged over 70, but it can occur at any age. It is more common in men than women. The much rarer nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) mostly affects children, or men in their 30s and 40s.

## Q: What are the symptoms?

**A:** Many people with Hodgkin lymphoma initially have few or only 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; and unexpected weight loss. 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:

**Certain viruses** – Infection with Epstein-Barr virus (glandular fever or infectious mononucleosis) or human immunodeficiency virus (HIV) increases the risk, but this explains 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 who has had Hodgkin lymphoma slightly increases a person's risk of developing it. However, this family link is uncommon.

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

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 during all stages of your cancer care as an adult with Hodgkin lymphoma, visit [cancerpathways.org.au/optimal-care-pathways/lymphoma](https://cancerpathways.org.au/optimal-care-pathways/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

<b>haematologist*</b>	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy and other drugs; usually the main specialist for Hodgkin lymphoma
<b>medical oncologist*</b>	treats cancer with chemotherapy and other drug therapies; in some cases, may be the main treating specialist instead of a haematologist
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>cancer care coordinator</b>	coordinates your 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)
<b>haematology nurse</b>	administers chemotherapy and other drugs, and provides care, information and support throughout treatment
<b>clinical trials nurse</b>	coordinates recruitment to clinical trials and acts as a link between you and the team 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.

<b>pharmacist</b>	dispenses medicines and gives advice about dosage and side effects
<b>dietitian</b>	recommends an eating plan to follow while you are in treatment and recovery
<b>social worker</b>	links you to support services and helps you with emotional, practical and financial issues
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems, including restoring movement and mobility and recommending aids and equipment
<b>counsellor, psychologist</b>	help you manage your emotional response to diagnosis and treatment
<b>symptom management or palliative care team</b>	specialise in pain and symptom control to improve quality of life

*\*Specialist doctor*



# Diagnosis

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

## 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.
- Excision biopsy helps ensure an accurate diagnosis. It is the preferred way to biopsy for Hodgkin lymphoma because it reduces the risk that the sample will be too small to analyse.

### Core biopsy

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

## Further tests

If the biopsy of the enlarged lymph node shows that you have Hodgkin lymphoma, your GP will refer you to a specialist such as a haematologist. 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 (see next page) and a PET-CT or CT scan (see pages 18–20). 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/or 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. However, once Hodgkin lymphoma has been diagnosed, you will have regular blood tests to check how the disease and/or its treatment are 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 test 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. These organs sometimes do not work properly if Hodgkin lymphoma is present. Further blood tests may help determine if the Hodgkin lymphoma is affecting your other organs.

## 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 three-dimensional colour image. It is available at many major hospitals, and can show whether the lymphoma has spread to the bone marrow. It can also be used later to check how the lymphoma has responded to treatment.



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.

If you are having a PET-CT scan, you will be asked not to eat or drink anything for several hours beforehand. 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 around 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 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 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.

**MRI scan** – MRI (magnetic resonance imaging) scans are not commonly used for people with Hodgkin lymphoma, but may be useful in some special circumstances, such as 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 usually takes about an hour.

### **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

still while a local anaesthetic is injected into your pelvis (hip). You may also be offered medicine to help you relax (light sedation). The doctor will first use a needle to remove a small sample of fluid from the bone marrow in your hip (bone marrow aspiration). Next, the doctor uses another needle to take a matchstick-width sample of both bone and bone marrow tissue (bone marrow trephine).

During the biopsy, you could feel some pressure or discomfort. If you feel uncomfortable afterwards, ask a member of your health care team about pain relief.

## Staging

Staging is a way of describing how far Hodgkin lymphoma has spread throughout the body. Your doctor can explain your stage to you. Stages I and II are considered early-stage lymphoma and stages III and IV are considered advanced-stage lymphoma. See the diagrams on the next page.

## Risk categories

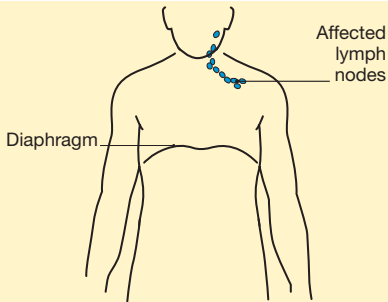
Your doctors will consider the stage along with the results of blood tests and imaging scans to work out how the Hodgkin lymphoma is likely to respond to treatment. Early-stage Hodgkin lymphoma may be grouped into “favourable” or “unfavourable” categories. Advanced-stage Hodgkin lymphoma will be given an International Prognostic Score (IPS) of 0–7 and categorised as low, medium or high risk.

Knowing the stage and risk category of the lymphoma helps your doctors work out the best treatment for you.

## Stages of Hodgkin lymphoma

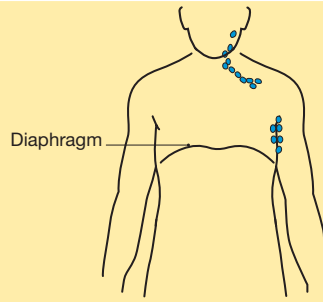
The stage indicates how far Hodgkin lymphoma has spread in the body. Each stage is also given a letter according to whether you are experiencing specific symptoms. The letter B means you have fever, night sweats and/or unexplained weight loss (typical lymphoma symptoms). The letter A means you have none of the B symptoms.

### Stage I



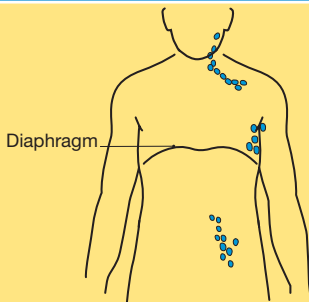
One lymph node area is affected, either above or below the diaphragm.

### Stage II



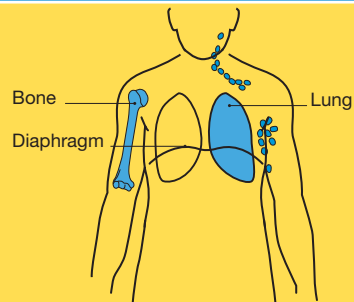
Two or more lymph node areas are affected on same side of the diaphragm.

### Stage III



At least one lymph node area above and at least one lymph node area below the diaphragm are affected.

### Stage IV



Lymphoma is in multiple lymph nodes and has spread to other parts of the body (e.g. bones, lungs, liver).



## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your haematologist (or medical oncologist if they are your main treating specialist). However, it is not possible for any doctor to predict the exact course of the disease in an individual person.

Important factors in assessing your prognosis include:

- your test results
- the type of Hodgkin lymphoma you have
- the stage and risk category
- the rate of cancer growth
- how well you respond to treatment (you will also have tests throughout your treatment that show how well the treatment is working)
- other factors such as your age, fitness and medical history.

Hodgkin lymphoma usually responds well to treatment, and most people who are treated for Hodgkin lymphoma go into remission. This means the symptoms of Hodgkin lymphoma decrease or 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 cancer hasn't returned.

In some 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 has been achieved. 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 your lymph nodes and the organs in your abdomen for swelling.

### 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 an excision biopsy (preferred for accuracy) or a core biopsy.

### Other tests

Other tests provide more information to help plan your treatment:

- Blood tests check 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 aspiration and trephine.

### Prognosis

Your doctor may talk to you about your prognosis or expected outcome.

- Your prognosis will depend on a number of 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 – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 14) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

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

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 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 that 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](http://australiancancertrials.gov.au).

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



# Treatment

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

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

A stem cell transplant (see pages 37–39) may be offered if Hodgkin lymphoma does not fully respond to initial treatment or returns after remission. Newer targeted therapy and immunotherapy drugs (see pages 40–41) may be an option for some people.

## 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](http://eviq.org.au), although your specialist may need to tailor the drugs to your individual situation. Your treatment team will give you information about your specific 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. 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) lines – inserted into the arm
- port-a-caths (ports) – a small device inserted under the skin of the chest or arm.

In most cases, you can 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, given in cycles spread over 3–6 months. Each cycle takes 2–4 weeks and includes some rest days. After the first two 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 how much chemotherapy you are given.

You will also have regular blood tests throughout your treatment. If your white blood cell count is low, you may be given injections of a substance known as granulocyte-colony stimulating factor (G-CSF), which can help to increase your white cell count and protect you from infection. Alternatively, you may need to have your chemotherapy delayed until your white cell count has improved.

## Fertility and cancer treatment

Some types of chemotherapy and radiation therapy can affect the ability to have children naturally. Men may produce fewer sperm, while some women will have irregular periods or menopause (when periods stop permanently). 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. Before treatment begins, men may be able to preserve some semen and women may be able to freeze embryos or eggs.

► See our *Fertility and Cancer* booklet.

## 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 will have few side effects, while others will experience a range. Most side effects are temporary and can be managed.

Before treatment, your health care team will discuss with you the potential side effects and how to manage them. Your doctor may give you medicines to relieve any symptoms you have. It is important to discuss any side effects from treatment with your doctor or nurse. They may need to closely monitor the problem or change your treatment.

Some of the common side effects experienced by people who receive chemotherapy for Hodgkin lymphoma are described on the next two pages.

## Common side effects of chemotherapy

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



### Increased risk of infections

Chemotherapy reduces your white blood cell level (neutropenia), making it harder for your body to fight infections. Colds and flu may be easier to catch and harder to shake off, and scratches or cuts may get infected more easily. You may also be more likely to catch a serious infection without any obvious cause and need to be admitted to hospital. See page 32 for ways to reduce your risk of infection.

### Nausea and vomiting

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

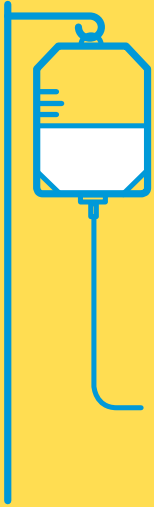
- ▶ See our *Nutrition and Cancer* booklet and listen to our “Appetite Loss and Nausea” podcast.



### 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 start to disappear after your treatment is finished, though they can last a long time or even be permanent.





### 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 blood transfusion to increase your platelet count.



### Hair thinning/hair loss

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

► See our *Hair Loss* fact sheet.



### Fatigue

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

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

### Dental problems

Your gums may look red, shiny or swollen, and they may bleed if your platelet count falls. Use a soft toothbrush to help prevent bleeding gums. See your dentist for regular check-ups and tell them you’re having chemotherapy. Check with your treatment team before having major dental work.

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



## Taking care with infections

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

### Reduce your risk

To prevent the spread of infection:

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

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

## Steroids

Steroids are substances made naturally in the body. They can also be produced artificially and used as a drug. The most commonly used steroids for Hodgkin lymphoma are prednisone or prednisolone. These are known as corticosteroids and they are different to the anabolic steroids sometimes used by bodybuilders.

You may be given steroids to increase the effect of the chemotherapy, help destroy the lymphoma, and treat any nausea and vomiting. Steroids are usually taken in tablet form, 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, feelings of restlessness, trouble sleeping (insomnia), weight gain and mood changes. If you need to take steroids for several months, you may experience a build-up of fluid in the body (fluid retention), high blood pressure, and high glucose levels (leading to diabetes in some people). You may also be more likely to get infections and, over time, your skin, muscles and bones may weaken. Your doctor will explain the risks and benefits of taking steroids in your case.

## Radiation therapy

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

## How radiation therapy is given

Radiation therapy for Hodgkin lymphoma is generally given after a course of chemotherapy. It usually involves multiple small doses over several days or weeks to increase the effect of the radiation therapy and reduce side effects. The length of treatment will depend on the size and stage of the Hodgkin lymphoma and your general health.

During treatment, you will lie under a large machine that directs radiation at the area affected by cancer. Each treatment session takes only a few minutes, but it can take longer to set up the equipment. Your first radiation therapy appointment will take 1–3 hours because you will see the radiation oncologist, have extra tests and have your treatment carefully planned. You can usually go home straight after each session.

## Side effects of radiation therapy

The most common side effects of radiation therapy are tiredness and lack of energy. 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, while radiation therapy to the neck can make your mouth and throat sore and dry, cause difficulty swallowing and affect your sense of taste. Treatment can also lead to skin changes such as red, dry and itchy skin at the treatment area.

Side effects can build up during the course of treatment, but most will be temporary. Talk to your treatment team about any side effects that concern you.

➤ See our *Understanding Radiation Therapy* booklet.

## Late effects of treatment

Some side effects from treatment may not show up until many months or years later. Your treatment will be carefully planned to reduce the risk of any of these late effects.

**Chemotherapy** – Chemotherapy can increase the risk of heart disease, although this is less common with the current treatment plans. Children and young people treated with some chemotherapy drugs may have a higher risk of developing a second cancer later.

**Radiation therapy** – In some cases, there may be an increased risk of developing another cancer near the area where radiation therapy was given. In the neck area, radiation therapy increases the risk of having a stroke or may cause an underactive thyroid gland, while in the chest, it can lead to heart disease and is associated with an increased risk of breast cancer in women.

Everyone should follow the general cancer screening guidelines, but people who have had chemotherapy or radiation therapy should start cancer screening at an earlier age. Talk to your specialist and your GP about when to start. Women who reach menopause early because of their lymphoma treatment may also be at increased risk of osteoporosis (when bones become weaker).

Your doctor will talk to you about late effects before treatment starts, but these effects are less likely now because staging and treatment of Hodgkin lymphoma have improved. However, if any symptoms appear, even many years after treatment, ask your GP whether they could be related to the treatment you had for Hodgkin lymphoma.



## Kim's story

A few months before my wedding in 2005, I saw my GP because I'd been feeling tired and had lost weight, but I was mostly worried about a lump in my neck. The doctor didn't have time to check it out properly and wasn't too worried, so I didn't think anything else of it.

Six months after my wedding, I noticed that the lump in my neck seemed to be getting bigger. My new GP referred me for an ultrasound and blood tests.

I then saw a specialist, who did a core biopsy on the spot. A few days later he called me and said, "Well, I think it's Hodgkin lymphoma." We'd discussed that possibility, so it wasn't a huge shock to me.

After an excision biopsy that confirmed the diagnosis, I had chemotherapy one day a fortnight for six months. The main side effect was nausea, but medication helped. I had at least a week between treatments where I felt fine. I even managed to finish all my uni assignments.

When my treatment ended, scans showed I was in remission, but I relapsed a year later.

I've relapsed a few times and had chemotherapy, radiation therapy and a stem cell transplant using my own stem cells. I then had a bone marrow transplant with my brother as the donor and went into remission. I've now been in remission for eight years.

Once I went into remission, I had a PET scan every year for five years. Now I visit my haematologist every year for blood tests and a general check-up.

It's taken me a number of years to get my stamina back to where I can work more hours and feel like I'm not constantly lacking energy. That's something I'll have to deal with for a while, but at least I'm healthy now.

## Stem cell transplant

If Hodgkin lymphoma comes back (relapses) or doesn't respond completely to initial treatment (refractory disease), you may need a stem cell transplant. This involves a course of intensive chemotherapy followed by a transplant of stem cells. You will need to repeat tests, such as PET-CT scans and blood tests, throughout the treatment.

Stem cells are unspecialised, blood-forming cells that can be taken from the bloodstream (peripheral blood stem cell transplant), bone marrow (bone marrow transplant) or, rarely, umbilical cord blood (cord blood transplant).

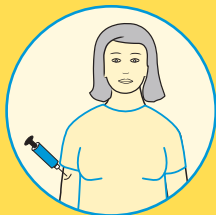
There are two main types of stem cell transplants. The most common type used for Hodgkin lymphoma is an autologous transplant, when your stem cells are removed from your blood and later transplanted back into your body. The other type is an allogeneic transplant, when the stem cells are collected from another person (a donor). The donor may be a family member or from a donor registry. Allogeneic transplants are less commonly used for Hodgkin lymphoma, as most people respond to treatment with either chemotherapy, radiation therapy or an autologous transplant.

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. The main steps in an autologous stem cell transplant are described on the next two pages. For more details about this or for information about allogeneic transplants, talk to your transplant team, contact the Leukaemia Foundation on 1800 620 420 or visit [leukaemia.org.au](http://leukaemia.org.au).

## Steps in an autologous stem cell transplant

This is a general outline of a transplant using your own stem cells, but the process varies. Your transplant team will provide you with more details.

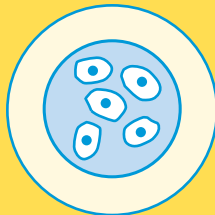
### 1 Stem cells stimulated



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

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

### 2 Stem cells collected



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

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

### 3 Stem cells preserved

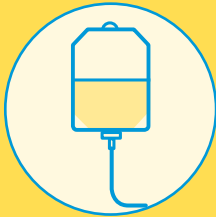


The stem cells are processed and frozen using liquid nitrogen. This is known as cryopreservation.

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



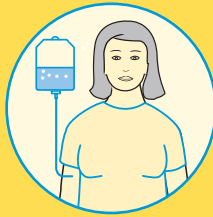
#### 4 High-dose chemotherapy



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

Side effects will be similar to those of standard chemotherapy but can be more intense. They may include nausea, diarrhoea, mouth sores, flu-like symptoms and high risk of infections (see pages 29–32).

#### 5 Stem cells transplanted



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

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

#### 6 Engraftment



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

In most cases, you will stay in hospital for 1–4 weeks until you are well enough to go home. Once home, you'll need check-ups every week or so, but these will usually become less frequent over time.

## Targeted therapy and immunotherapy

People with Hodgkin lymphoma that has come back (relapsed) or hasn't fully responded to initial treatment (refractory) may be able to have new drug therapies in certain circumstances.

Targeted therapy drugs attack specific particles (molecules) in 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. It is available through the Pharmaceutical Benefits Scheme (PBS) for some people with relapsed or refractory Hodgkin lymphoma. It is sometimes used before an allogeneic stem cell transplant while waiting for a donor. Brentuximab vedotin is given into a vein through a drip (intravenous infusion). Side effects may include nausea, fatigue, increased risk of infection and bleeding, and numbness and tingling in the hands and feet (peripheral neuropathy).

Another targeted therapy drug called rituximab may be offered to people with nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL). Common side effects include increased risk of infection and bleeding, nausea, hair loss, skin rash, fever and headaches.

Immunotherapy uses the body's own immune system to fight cancer. An immunotherapy drug called pembrolizumab is available on the PBS for some people with relapsed or refractory Hodgkin lymphoma. It is given as an intravenous infusion. Side effects include diarrhoea, rash, fever, aches and pains, and fatigue. While many people experience only mild side effects, others can have serious side effects affecting organs such as the liver and lungs. Your treatment team will monitor you closely and explain what to watch out for.

Other targeted therapy and immunotherapy drugs for Hodgkin lymphoma may be available through clinical trials (see page 26).

Ask your doctor about the latest developments.

- ▶ See our *Understanding Targeted Therapy* and *Understanding Immunotherapy* fact sheets.

## Palliative treatment

If Hodgkin lymphoma or its treatment is causing symptoms that are hard to manage, your doctor may suggest you see experts in symptom management, sometimes called the palliative care team. They can help to improve your quality of life by offering palliative treatment, which manages symptoms of cancer 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 and you can often still have active treatment for the Hodgkin lymphoma.

As well as slowing the spread of Hodgkin lymphoma, palliative treatment can relieve any pain and help manage other symptoms such as nausea and vomiting, constipation and diarrhoea. Treatment options may include radiation therapy, chemotherapy or other medicines. If you are experiencing ongoing symptoms, ask for a referral to the symptom management or palliative care team.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, cultural, spiritual and social needs. The team also supports families and carers.

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



## 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.
- Radiation therapy uses targeted radiation to kill or injure cancer cells so they cannot multiply. Side effects depend on the area of your body that is treated. For example, radiation therapy to the neck can make your mouth and throat sore and dry.

### 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). You will have high-dose chemotherapy before the transplant, which will cause side effects. This treatment can take several months.
- People with relapsed or refractory Hodgkin lymphoma may be able to have targeted therapy or immunotherapy drugs in certain circumstances.
- Palliative treatment can be used at any stage of advanced cancer to control symptoms and stop the cancer 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](http://cancercouncil.com.au).

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

➤ See our *Nutrition and Cancer* booklet.

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

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

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

➤ See our *Understanding Complementary Therapies* booklet.



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

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

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

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

➤ See our *Emotions and Cancer* booklet.

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

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

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

➤ See our *Fertility and Cancer* booklet.



# Life after treatment

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

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

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

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

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

## 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. 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.

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 approaching, 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 Hodgkin lymphoma returns?

For some people, Hodgkin lymphoma does come back after treatment, which is known as a relapse or recurrence. This is why it's important to have regular check-ups.

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





# 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 depending on where you live.

### Cancer Council 13 11 20

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



### Information resources

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

### Practical help

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



### Legal and financial support

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

### Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit **[cancercouncil.com.au/OC](http://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	<a href="http://cancerCouncil.com.au">cancerCouncil.com.au</a>
Cancer Council Online Community	<a href="http://cancerCouncil.com.au/OC">cancerCouncil.com.au/OC</a>
<i>The Thing About Cancer</i> podcast	<a href="http://cancerCouncil.com.au/podcasts">cancerCouncil.com.au/podcasts</a>
Cancer Australia	<a href="http://cancerAustralia.gov.au">cancerAustralia.gov.au</a>
eviQ	<a href="http://eviq.org.au">eviq.org.au</a>
Arrow Bone Marrow Transplant Foundation	<a href="http://arrow.org.au">arrow.org.au</a>
Australasian Leukaemia & Lymphoma Group	<a href="http://allg.org.au">allg.org.au</a>
Australian Bone Marrow Donor Registry	<a href="http://abmdr.org.au">abmdr.org.au</a>
Australian Cancer Trials	<a href="http://australiancancertrials.gov.au">australiancancertrials.gov.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Leukaemia Foundation	<a href="http://leukaemia.org.au">leukaemia.org.au</a>
Lymphoma Australia	<a href="http://lymphoma.org.au">lymphoma.org.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
Leukemia & Lymphoma Society (US)	<a href="http://lls.org">lls.org</a>
Lymphoma Research Foundation (US)	<a href="http://lymphoma.org">lymphoma.org</a>



# Caring for someone with cancer

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

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

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://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 Associations** – Carers NSW, a statewide organisation specifically for carers, can also provide support. Call 1800 242 636 or visit [carersnsw.org.au](http://carersnsw.org.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit [cancercouncil.com.au](http://cancercouncil.com.au) to find out more about carers' services.

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



# 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?
- Where is the lymphoma? What stage and 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?
- 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 I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- 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.

## **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. Apheresis is one of the key steps in a stem cell transplant.

## **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 red blood cells, white blood cells and platelets.

## **bone marrow aspiration**

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

## **bone marrow trephine**

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

## **B symptoms**

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

## **chemotherapy**

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

## **classical Hodgkin lymphoma**

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

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create cross-sectional 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.

**extranodal lymphoma**

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

**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. It is given either as an injection or through a drip into the bloodstream (intravenously).

**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. See also non-Hodgkin lymphoma.

**immune system**

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

**immunotherapy**

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

**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.

**lymph fluid**

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

**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, thymus and lymph nodes.

**lymph nodes**

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

**lymphocyte**

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

**lymphoma**

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

### **lymph vessels**

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

### **MRI scan**

Magnetic resonance imaging scan. This scan uses a magnet 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.

### **nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)**

An uncommon type of Hodgkin lymphoma.

### **non-Hodgkin lymphoma**

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

### **palliative treatment**

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

### **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). This damage can be a side effect of chemotherapy.

### **PET scan**

Positron emission tomography scan. For this scan, a person is injected with a small amount of radioactive glucose solution to help find cancerous areas.

### **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**

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

### **red blood cells**

One of 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 called 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 or radiation therapy, then replaced by healthy stem cells. The healthy stem cells may come from the bone marrow (bone marrow transplant), from the bloodstream (peripheral blood stem cell transplant) or from umbilical cord blood (cord blood transplant).

**steroids**

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

**systemic treatment**

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

**targeted therapy**

Drugs that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

**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 produce white blood 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 on either side of 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](http://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. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Hodgkin lymphoma*, AIHW, Canberra, 2018.



## How you can help

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

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

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

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

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

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

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council

## 13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



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

For further information and details, visit our website, [cancercouncil.com.au](http://cancercouncil.com.au).

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