



# Understanding Hodgkin Lymphoma

A guide for people with cancer,  
their families and friends

Cancer  
information

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### Note to reader

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

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

### Cancer Council NSW

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



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# Introduction

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, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

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. You may also like to pass this booklet to your 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. Turn to the last page of this book for more details.



**Cancer  
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13 11 20**

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# What is blood cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. Our bodies constantly make new cells to help us grow, replace worn-out tissue and heal damaged cells after an injury. Normally, cells grow, multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

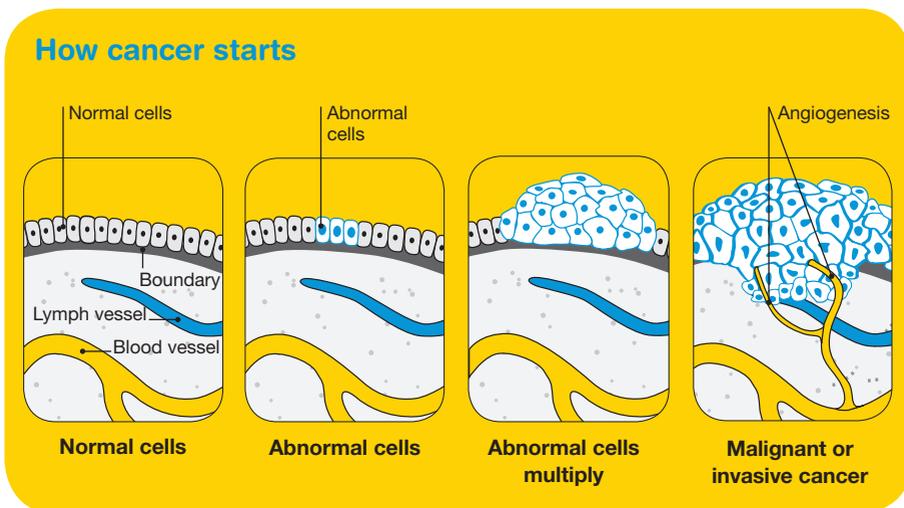
A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels in a process called angiogenesis.

Blood cancer is a broad term for cancers that affect the blood, bone marrow and lymphatic system. There are three main groups of blood cancers: leukaemia, lymphoma and myeloma.

Lymphoma is a term used to describe cancers of the lymphatic system (see pages 6–8). Lymphomas begin in the white blood cells called lymphocytes. When lymphocytes become damaged, they grow and multiply uncontrollably, causing enlarged lymph nodes.

If these abnormal cells continue to build up, they can spread and form a tumour in any part of the lymphatic system. As the damaged lymphocytes replace normal cells, the body's immune system often becomes less able to resist and fight infections.

Sometimes other types of cancer spread (metastasise) to the lymph nodes. This is not lymphoma. For example, breast cancer that has spread to the lymph nodes is called secondary or metastatic breast cancer.





# 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 consists of:

**Lymph vessels** – These thin tubes form a network 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 removing bacteria and cell debris, before being emptied into the bloodstream.

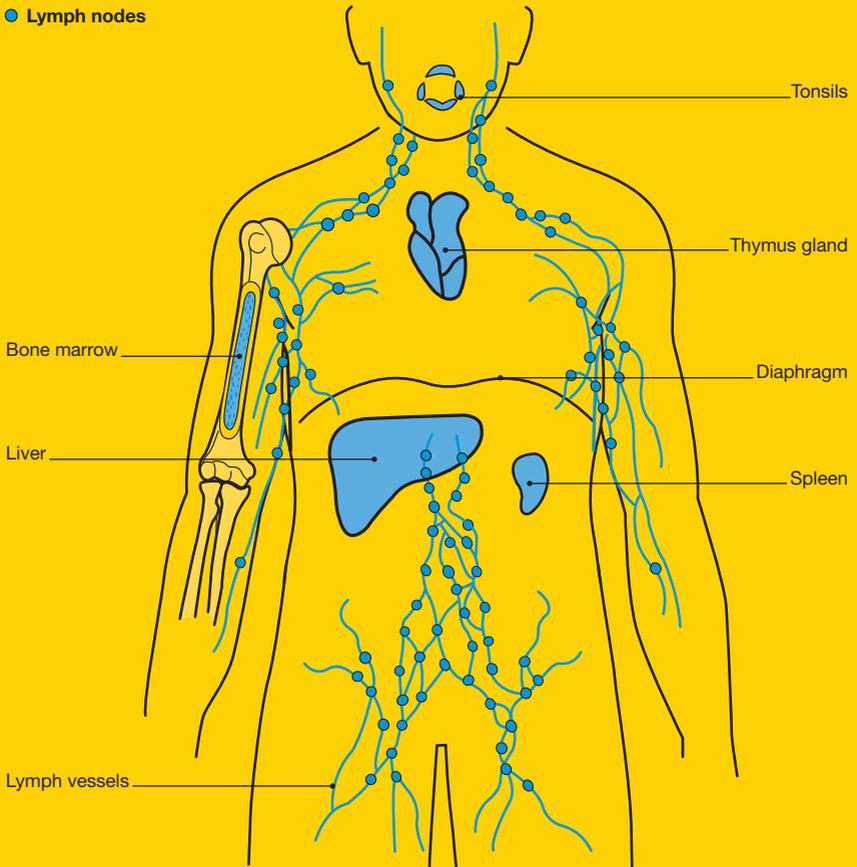
**Lymph nodes (glands)** – These small, bean-shaped structures are found along the lymph vessels. Lymph nodes are located in groups throughout the body, including the neck, underarms, chest, abdomen and groin. The lymph nodes filter the lymph fluid as it passes through the body, removing and destroying bacteria, viruses and other harmful substances.

**Lymph tissue** – This includes the lymph nodes, spleen, bone marrow, thymus, tonsils, and some tissues in the digestive tract.

The lymph nodes, lymph tissue and lymph fluid all contain white blood cells called lymphocytes, which help fight infection. When germs become trapped in the lymph nodes, they become swollen, which is a sign that your body is fighting an infection. For example, the glands 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.

# Anatomy of the lymphatic system

● Lymph nodes



The lymphatic organs include:

**Thymus gland** – This is found inside the rib cage, behind the breastbone. The thymus gland helps produce white blood cells.

**Bone marrow** – This is the soft, spongy material inside bones. Bone marrow produces three types of blood cells: oxygen-carrying red blood cells; infection-fighting white blood cells, including lymphocytes; and platelets, which help the blood to clot.

**Spleen** – The spleen is found on the left side of the abdomen, under the ribs. It stores lymphocytes, filters waste products from the blood, and destroys old blood cells, abnormal cells and bacteria.

**Tonsils** – The tonsils are two small collections of lymphatic tissue at the back of the throat that trap inhaled or ingested germs.

### **Different types of 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 usually seen in Hodgkin lymphoma, but it is not found in non-Hodgkin lymphoma. For a free booklet about non-Hodgkin lymphoma, call Cancer Council **13 11 20** or visit [cancercouncil.com.au](http://cancercouncil.com.au) to download a digital version.



## Key questions

### Q: What is Hodgkin lymphoma?

**A:** Hodgkin lymphoma is a blood cancer that begins in the white blood cells called lymphocytes (see page 5). It is sometimes called Hodgkin disease. The name Hodgkin comes from the doctor who first described this cancer.

Hodgkin lymphoma 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 can appear 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.

### Q: What types are there?

**A:** There are two different types of Hodgkin lymphoma: classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (see box, page 10). These two types differ in how they look under the microscope, and how they grow and spread.

About 95% of all cases of Hodgkin lymphoma are classical Hodgkin lymphoma. The cells of this type of Hodgkin lymphoma are called Reed-Sternberg cells.

There are four subtypes of classical Hodgkin lymphoma. Each one looks different under a microscope, grows in its own way and involves different sites of the body. They are:

- **nodular sclerosis** – the most common subtype; affects 60–80% of people with Hodgkin lymphoma
- **mixed cellularity** – affects 25–30% of people with Hodgkin lymphoma and is usually more advanced at diagnosis
- **lymphocyte-rich** – affects 5% of people with Hodgkin lymphoma
- **lymphocyte-depleted** – affects fewer than 5% of people with Hodgkin lymphoma.

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

NLPHL occurs in fewer than 5% of people with Hodgkin lymphoma. It mostly affects children or men in their 30s and 40s. The main symptom is enlarged lymph nodes in the neck, chest, armpit or groin.

NLPHL is usually diagnosed via excision biopsy (see page 13). The cells in NLPHL differ from classical Hodgkin lymphoma. They are known as “popcorn cells” because of how they look under a microscope.

The management of NLPHL is different from classical Hodgkin lymphoma. Sometimes, the only treatment for NLPHL is an operation to remove the lymph nodes, followed by regular check-ups to make sure the cancer hasn’t returned. This is called “watch and wait”.

Other treatments for NLPHL include radiotherapy and chemotherapy. To find out more about NLPHL, talk to your haematologist.

## Q: What are the symptoms?

**A:** The most common symptom of Hodgkin lymphoma is a painless swelling in the neck, under the arm or in the groin. This swelling is caused by enlarged lymph nodes. Other symptoms may include:

- unexplained fever
- excessive sweating, particularly at night
- unintentional weight loss
- persistent tiredness
- persistent rash or itching
- unexplained cough
- shortness of breath.

These symptoms are common to many conditions, such as the flu or other viruses. Most people with these symptoms do not have Hodgkin lymphoma. However, if you have these symptoms and there is no obvious cause, such as an infection, see your doctor.

## Q: What are the risk factors?

**A:** The causes of Hodgkin lymphoma are largely unknown. Researchers think a combination of factors relating to a person's genes and their environment may cause Hodgkin lymphoma. Risk factors include:

**Epstein-Barr virus and HIV** – People who have a history of infection with Epstein-Barr virus (also called glandular fever or infectious mononucleosis) or human immunodeficiency

virus (HIV) have a higher chance of developing classical Hodgkin lymphoma. However, this accounts for only a small proportion of people who have 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 and most people with Hodgkin lymphoma do not have a family history.

**Weakened immune system** – This could be caused by an autoimmune disease, having undergone immune suppression or taking certain medicines 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.

## **Q: How common is it?**

**A:** Hodgkin lymphoma is a rare form of cancer – it makes up only about 0.5% of all cancers diagnosed in Australia.<sup>2,3</sup>

About 11% of all lymphomas diagnosed are types of Hodgkin lymphoma. The rest are non-Hodgkin lymphoma.

Each year in NSW, about 200 people are diagnosed with Hodgkin lymphoma. It most commonly develops in younger people aged 15–29 and older people aged over 65, but it can occur at any age. It is more common in men than women.



# Diagnosis

If your general practitioner (GP) suspects that you have Hodgkin lymphoma, you will have a physical examination. Your 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 (tissue sample).

## Biopsy

Removing some cells and tissue from an enlarged lymph node for examination under a microscope is the most common way to diagnose and classify Hodgkin lymphoma. 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 under anaesthetic (either a local or general depending on the location of the lymph node).
- You may have day surgery or you may be in hospital for a few days.
- The wound will usually be closed with stitches.
- This is the preferred type of biopsy for Hodgkin lymphoma because it reduces the risk that the sample size will be too small to analyse.
- This type of biopsy helps ensure an accurate diagnosis and staging of any lymphoma found.

### Core needle biopsy

- A hollow needle is inserted into the lymph node to remove some cells and a small piece of tissue.
- Ultrasound or CT scan may be used to guide the needle to the correct node.
- You can have this procedure as day surgery with a local anaesthetic.
- This type of biopsy is usually done when it will be difficult to remove the lymph node or when Hodgkin lymphoma has recurred.
- Depending on the pathology results, you may need to have a follow-up excision biopsy.

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

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 lymph node shows you have Hodgkin lymphoma, you will have a number of additional tests to find out whether the cancer has spread to other areas of your body. This is called staging (see page 18).

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 below) and some imaging tests (see pages 15–17). Some tests may be repeated during or after treatment to check your health and how well the treatment is working.

## Blood tests

You will have regular blood tests to check your total number of red blood cells, white blood cells and platelets. Each type of blood cell performs a different function, such as carrying oxygen around your body (red blood cells), fighting infection (white blood cells), and helping your blood to clot (platelets).

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 tests described below.

**Chest x-ray** – You may have an x-ray of the chest to check whether the Hodgkin lymphoma has spread to the lymph nodes in your chest or to your lungs.

**CT scan** – A CT (computerised tomography) scan uses x-rays and a computer to create a detailed picture of an area inside the body. You will have a CT scan of your neck, chest and abdomen to diagnose Hodgkin lymphoma.

You may have a special dye 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. This dye can cause allergies in some people. If you have had an allergic reaction to iodine or dyes during a previous scan, tell the medical team beforehand. You should also tell the doctor if you're diabetic, have kidney disease or are pregnant.

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.



The radiation that's absorbed into your body during a PET scan is generally not harmful and will leave your body within a few hours. Talk to your doctor before the scan if you are concerned.

**PET scan** – During a PET (positron emission tomography) 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 you will be scanned. The scan itself will take around 30 minutes. Let your doctor know if you are claustrophobic, as the scanner is a confined space.

**PET-CT scan** – A PET scan combined with a CT scan is a specialised test available at many major metropolitan hospitals. It produces a three-dimensional colour image. The CT helps pinpoint the location of any abnormalities revealed by the PET scan. This test may help show whether the lymphoma has spread to the bone marrow.

**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 needle biopsy (see page 13). 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. The MRI scan uses a combination of magnetism 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. The scan is usually complete in about one hour.

## **Bone marrow biopsy**

You may have a biopsy to check whether the bone marrow contains cancer cells. A bone marrow biopsy consists of two steps:

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

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

You will lie still while a local anaesthetic is injected into your pelvis (hip). You may also be offered light general sedation. You may feel some pressure or discomfort during the biopsy – this usually lasts no more than a day. Ask a member of your health care team about pain-relieving medicines if you feel uncomfortable after the procedure.

## Staging

Different stages describe how far Hodgkin lymphoma has spread throughout the body. Staging helps your doctors recommend the best treatment for you. Your doctor can explain your stage to you. As well as a number (see table below), each stage is also assigned a letter according to whether you are experiencing specific symptoms:

- ‘A’ means you have none of the usual symptoms of Hodgkin lymphoma, such as night sweats and fever.
- ‘B’ means you have symptoms such as fever, night sweats or unexplained weight loss.

### Stages of Hodgkin lymphoma

Stage I	One lymph node area is affected. This is either above or below the diaphragm.
Stage II	Two or more lymph node areas are affected, either above or below the diaphragm.
Stage III	Lymph node areas on both sides of the diaphragm are affected.
Stage IV	Lymphoma is in multiple lymph nodes, and has spread to other parts of the body (e.g. bone marrow, liver, lungs).

## 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.

Test results, the type of Hodgkin lymphoma you have and its stage, the rate of cancer growth, how well you respond to treatment, and other factors such as your age, fitness and medical history are all important factors in assessing your prognosis. You will also have tests throughout your treatment that show how well the treatment is working.

Hodgkin lymphoma responds well to treatment and most people who are treated for Hodgkin lymphoma go into remission. Remission occurs when symptoms of Hodgkin lymphoma decrease or disappear and there is no evidence of disease on physical examination or imaging tests. During remission, you will need regular check-ups to ensure that you are still healthy and the cancer hasn't returned.

Hodgkin lymphoma may come back (recur) in some cases. See page 42 for more information about treatment for recurrence.

## Which health professionals will I see?

Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a haematologist (or medical oncologist), who will arrange further tests and advise you about your treatment options.

You will probably be cared for by a range of health professionals, called a multidisciplinary team (MDT), who will be responsible for different aspects of your treatment. Turn the page for a list of people who make up this MDT.

Health professional	Role
<b>haematologist*</b>	specialises in diagnosing and treating diseases of the blood, the lymphatic system and bone marrow; coordinates all aspects of patient care, including drug therapies such as chemotherapy, immunotherapy and targeted therapy (systemic treatment), and referral for radiotherapy if required
<b>medical oncologist*</b>	treats cancer with drug therapies; in some cases, may be the main treating specialist instead of a haematologist
<b>radiation oncologist*</b>	prescribes and coordinates the course of radiotherapy; advises about side effects
<b>cancer care coordinator, clinical nurse consultant</b>	supports patients and families throughout treatment; liaises with other members of the health care team
<b>nurse</b>	helps administer drugs, including chemotherapy; provides care, information and support throughout all stages of treatment
<b>dietitian</b>	recommends an eating plan to follow during treatment and recovery
<b>social worker</b>	provides emotional support and helps with practical issues such as accommodation, travel, legal and financial concerns
<b>counsellor, psychologist</b>	provide counselling and emotional support
<b>physiotherapist, occupational therapist</b>	help with physical or practical issues

\* Specialist doctor



## Key points

- If your GP suspects that you have Hodgkin lymphoma, you will have a physical examination to check your lymph nodes for swelling. The GP will also feel your abdomen to check for swollen organs.
- 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 or a core needle biopsy. Excision biopsy is the preferred type of biopsy for diagnosing Hodgkin lymphoma.
- A blood test will check how well your bone marrow, kidneys and liver are working. Once the diagnosis is confirmed, you will have regular blood tests to track the progress of the disease.
- After the diagnosis is confirmed, you will have further tests to work out how far the Hodgkin lymphoma has spread. This is called staging. These tests may include a chest x-ray; CT, PET or PET-CT scan; ultrasound; and bone marrow aspiration and trephine.
- Your doctor may talk to you about your prognosis. This means the expected outcome of a disease. Most people with Hodgkin lymphoma go into remission after initial treatment.
- Your treatment team will be made up of a range of health professionals. They include your GP, a haematologist or medical oncologist, nurses, cancer care coordinator and social worker.



# 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. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

## Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 47 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor 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 doctor who provided the second opinion.

## Taking part in 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.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. To find out more, call 13 11 20 and ask for a free copy of *Understanding Clinical Trials and Research*, or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Treatment

The most important factor in planning treatment for Hodgkin lymphoma is the stage of the disease. Your 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 radiotherapy are the main treatments for Hodgkin lymphoma. These are often combined to improve treatment outcomes. People with more advanced Hodgkin lymphoma, or Hodgkin lymphoma that has come back after treatment, may have a stem cell transplant (see pages 33–36).

## Preparing for treatment

- Some types of chemotherapy can affect the way your heart and lungs work. Your doctor may recommend you have some tests before, during or after treatment to test your heart and lung functions.
- If fertility is a concern for you, ask your doctor before treatment starts about your risk of becoming infertile. Men may be able to preserve some semen before treatment and women may be able to freeze embryos or eggs. Call 13 11 20 and ask for our *Fertility and Cancer* booklet, or download a copy from [cancercouncil.com.au](http://cancercouncil.com.au).



This chapter provides information about treatment for Hodgkin lymphoma in adults. For information about treatment for children, see [childrenscancer.canceraustralia.gov.au](http://childrenscancer.canceraustralia.gov.au).



You may be able to access new targeted therapy (for example, brentuximab vedotin) and immunotherapy drugs to treat Hodgkin lymphoma through clinical trials. Talk with your doctor about the latest developments and whether you are a suitable candidate.

## Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. It is used to treat most cases of Hodgkin lymphoma.

Chemotherapy is usually given by inserting a needle into a vein (intravenously). Less commonly, chemotherapy is given as tablets or capsules. You will usually have chemotherapy as an outpatient.

The chemotherapy drugs you receive depend on the stage of the cancer and your general health. For Hodgkin lymphoma, a combination of several drugs is usually given in repeating cycles spread over 3–6 months. Each cycle takes several weeks – you will receive treatments on some days at the beginning of each cycle, followed by rest days. Your treatment team will provide details about your specific schedule.

During treatment, you will have regular blood tests. If your white 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. Otherwise, you may need to have your chemotherapy delayed until your white cell count has improved.

## Having steroids with chemotherapy

Steroids are made naturally in the body. They can also be produced artificially and used as a drug. Steroids are sometimes given with chemotherapy drugs to increase their effectiveness and help destroy the lymphoma. The most commonly used steroids for Hodgkin lymphoma are prednisone or prednisolone. Your doctor will advise you about possible side effects to look out for.

## Side effects of chemotherapy

Chemotherapy drugs affect both cancer cells and healthy cells in your body. This causes side effects. Some people will have no 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.

Some side effects such as hair loss can have an impact on your appearance and self-esteem. Others can be very emotionally challenging – for example, infertility can make people feel a sense of loss. If you have a partner, talking can help. Discussing your situation with a counsellor can also be beneficial. For more information on sexuality, intimacy and fertility, see page 40.

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 side effects experienced by people who have chemotherapy for Hodgkin lymphoma are:

**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.

**Nausea and vomiting** – Nausea (feeling sick) and vomiting are common. Anti-nausea medicines can be helpful.

**Increased risk of infections** – Chemotherapy reduces your white blood cell level, making it harder for your body to fight infections. Colds and flu may be easier to catch and harder to shake off, and scratches or cuts may get infected more easily. You may also be more likely to catch a more serious infection without any obvious cause and need to be admitted to hospital. See page 29 for ways to reduce your risk of infection.

**Heavy bleeding from minor cuts, or bruising easily** – A drop in the number of platelets in your blood can cause heavy bleeding from small cuts or make you more prone to bruises. 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.

**Nerve and muscle effects** – Some chemotherapy drugs can cause nerve damage (peripheral neuropathy). Symptoms can include tingling, pain or loss of sensation 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.

**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. Tell them you're having chemotherapy. Check with your treatment team before having major dental work.

**Menopause** – Chemotherapy can damage the ovaries, bringing on menopause in some women. Menopause is when periods stop completely, causing infertility. Menopause can increase the risk of osteoporosis (when bones become weaker and break more easily).

**Infertility** – Most people treated for Hodgkin lymphoma do not become infertile. In men, chemotherapy may lower the number of sperm produced, and reduce their ability to fertilise a woman's egg. This can cause infertility, which may be temporary or permanent. Some women will experience irregular periods during treatment.



To find out more, call Cancer Council **13 11 20** for free copies of *Understanding Chemotherapy, Nutrition and Cancer* and *Fertility and Cancer*, or download them from [cancercouncil.com.au](http://cancercouncil.com.au).

## Taking care with infections

If white blood cell numbers drop during treatment, you may be more likely to catch colds, flu or more serious infections requiring 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, if they are able and willing to do so
- 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
- ensure you prepare and store food properly to avoid foodborne illnesses and food poisoning.

### 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 fever of 38°C or higher
- chills or shivering
- sweating, especially at night
- burning or stinging when urinating
- a severe cough or sore throat
- vomiting that lasts more than a few hours
- unusual bruising or bleeding, such as nosebleeds, blood in your urine or black bowel motions
- severe abdominal pain, constipation or diarrhoea
- tenderness, redness or swelling around the site of the intravenous chemotherapy device.

## Radiotherapy

Radiotherapy (also known as radiation therapy) uses high-energy gamma rays or x-rays to kill or damage cancer cells. It is generally given after the course of chemotherapy. Your treatment will be carefully planned to do as little harm as possible to your healthy cells.

The treatment is usually given as multiple small doses over several days or weeks to maximise the effect of the radiotherapy 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 radiotherapy appointment will take 1–3 hours, as you will see the radiation oncologist, have extra tests and have your treatment carefully planned.

You may have PET-CT scans during your course of radiotherapy to see if any changes need to be made to your treatment plan.

### Side effects of radiotherapy

The most common side effects of radiotherapy are tiredness and lethargy. Other side effects will depend on the part of the body being treated: radiotherapy to the abdomen may cause an upset stomach and diarrhoea; and radiotherapy 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.

For suggestions on managing these and other side effects of radiotherapy, call Cancer Council 13 11 20 or download a copy of *Understanding Radiotherapy* from [cancerCouncil.com.au](http://cancerCouncil.com.au).

## Late effects of treatment

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

**Chemotherapy** – Some chemotherapy drugs may increase the chance of developing a second cancer later in life. Chemotherapy can also increase your risk of heart disease, although this is less common with the current chemotherapy treatment plans.

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

Ongoing research continues to find ways to improve treatments and reduce any late effects while maintaining the high remission rate of Hodgkin lymphoma. It is important that you talk to your doctor about any symptoms that appear, even many years after treatment.



## Kim's story

A few months before my wedding in 2005, I saw my GP as 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 needle 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 confirmed the diagnosis, I had chemotherapy one day a fortnight for six months. The main side effect I had 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, radiotherapy and an autologous stem cell transplant. After a bone marrow transplant with my brother as the donor, I 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

Stem cells are unspecialised blood-forming cells that form in the bone marrow. If Hodgkin lymphoma comes back (recurs or relapses) or doesn't respond completely to initial treatment, you may need high doses of chemotherapy to help destroy the cancer cells. This can also damage the stem cells, and you may need a stem cell transplant to help restore the bone marrow and rebuild your immune system.

A transplant is done in several stages and the entire procedure, including recovery, can take months. There are two main types:

**Autologous transplant** – when your stem cells are removed from your blood and later transplanted (reinfused) back into your body.

**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. This type of transplant is less common, as most people with Hodgkin lymphoma respond to treatment with either chemotherapy, radiotherapy or an autologous transplant.

### Pre-transplant assessment

A stem cell transplant is a major procedure and not all people are suitable candidates. Your doctors will talk to you about what is involved and you will have a range of tests to assess your ability to handle the transplant process. Your test results, age and overall fitness are important factors in assessing whether you will be able to tolerate the high-dose chemotherapy (see page 35).

## Autologous stem cell transplant steps

This is a general outline of a transplant using your own stem cells. The process varies from person to person. Detailed information is available from [leukaemia.org.au](http://leukaemia.org.au).

### 1 Mobilising stem cells

- The first stage is to stimulate the production of stem cells.
- You will usually be given a dose of chemotherapy followed by a special growth factor drug called granulocyte-colony stimulating factor (G-CSF).
- In some hospitals, you may just have the G-CSF without the chemotherapy.
- You will be given G-CSF for 5–10 days to help the stem cells multiply and move out of the bone marrow into the blood. This process is called mobilisation and takes several days.
- You will have regular blood tests to check whether there are enough stem cells in your blood.

### 2 Collecting and storing stem cells

- When enough stem cells have been made, they are collected from your blood via a process called apheresis.
- During apheresis a needle called a cannula is inserted into a vein in each arm. Blood is taken from your body through one of the cannulas and passed through a machine called a cell separator, which spins the blood and separates it into its different layers.
- After stem cells are collected from the white blood layer, the blood is returned to your body through the other cannula.
- Blood is removed and returned to your body in a continuous process. Only a small amount of your blood will be out of your body at any one time.
- You will be connected to the apheresis machine for 3–4 hours.
- The stem cells are processed and frozen using liquid nitrogen (cryopreserved).
- You will then have a rest period at home for about a month before the next stage.

### 3 Receiving high-dose chemotherapy

- In the week before the transplant, you'll have high-dose chemotherapy to kill the Hodgkin lymphoma cells. This will also destroy the stem cells in the bone marrow.
- Before and after the chemotherapy is given, you will have fluids through a drip to prevent dehydration and kidney damage. You may experience side effects, such as nausea, diarrhoea and mouth sores, from the chemotherapy.
- Because your stem cells have been destroyed, your blood count will be low and you will be more at risk of infections (see page 29).

### 4 Transplanting stem cells and engraftment

- A day or so after high-dose chemotherapy, your frozen stem cells are thawed and put back into your body (reinfused) using a drip. This process is similar to a blood transfusion and takes about an hour.
- You may have stomach cramps and feel nauseous, which can be managed with medicines.
- The healthy stem cells will travel via your bloodstream into your bone marrow, to restore the stem cells destroyed by the chemotherapy.
- This is called engraftment and takes about 10–14 days.

## **Bone marrow transplant**

Sometimes the stem cells are taken directly from the bone marrow, either from you or a donor. Under a general anaesthetic, the bone marrow is collected using a needle and syringe. It is processed to remove the fat cells, and the leftover stem cells are stored and frozen until you need a transplant. This type of stem cell collection is much less common nowadays.

## **Recovery and side effects after a transplant**

After the stem cell transplant, you will be in hospital for about 1–4 weeks, depending on the type of transplant you have, whether it is done as an outpatient or inpatient procedure, whether you have any other health problems, and the side effects that you experience. You will be able to leave hospital once your blood counts have returned to safe levels.

Your blood counts and general health will be monitored regularly by your doctor after the transplant. You may need occasional blood and platelet transfusions for a short period after the transplant. You may be given antibiotics to treat infections and will need to avoid contact with people with a cold, flu or other contagious infection.

Many transplant side effects are similar to the side effects of chemotherapy, but can be more severe. They include: nausea and vomiting; hair loss; infection (see page 29); bruising and bleeding; and fatigue. Your doctor and nurses will help you manage any side effects you experience after a stem cell transplant.

## Palliative treatment

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

Many people think that palliative treatment is for people at the end of their life; however it may be beneficial for people at any stage of advanced cancer. It is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve any pain and help manage other symptoms. There is no single program of palliative treatment – the treatment you are offered will be tailored to your individual needs. Treatment may include radiotherapy, chemotherapy or other medicines.

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

For more information or free booklets about *Palliative Care* and *Living with Advanced Cancer*, call Cancer Council 13 11 20 or visit [cancercouncil.com.au](http://cancercouncil.com.au).

“ I've been having palliative care treatment for five years. I'm not trying to get rid of the disease, just keeping it under control – and my quality of life is excellent. ” *Kate*



## Key points

- Your treatment will be based mainly on the stage of the Hodgkin lymphoma. Other factors include your age, symptoms and general health.
- The main treatments for Hodgkin lymphoma are chemotherapy and radiotherapy.
- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. Most people with Hodgkin lymphoma will receive chemotherapy. Side effects of chemotherapy include fatigue, nausea, increased risk of infections and hair loss.
- Radiotherapy uses x-rays to kill or injure cancer cells so they cannot multiply. Side effects depend on the area of your body that is treated. For example, radiotherapy to the neck can make your mouth and throat sore and dry.
- Some people have late side effects of chemotherapy or radiotherapy. These side effects include an increased risk of heart disease. Your treatment team will discuss these late effects with you.
- A stem cell transplant may be an option if the Hodgkin lymphoma returns or does not respond to other treatments. An autologous stem cell transplant is when your own stem cells are used; an allogeneic transplant is when stem cells are collected from another person (donor).
- Stem cell transplants can cause several side effects. These depend on the type of transplant you have. Your doctor will discuss the side effects you may experience.
- Palliative treatment may be given to relieve the symptoms of Hodgkin lymphoma without trying to cure it.



# Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to 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.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or visit [cancercouncil.com.au](http://cancercouncil.com.au).

## Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

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.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call Cancer Council 13 11 20 for free copies of *Sexuality, Intimacy and Cancer*, *Emotions and Cancer* and *Fertility and Cancer*, or download the booklets from [cancercouncil.com.au](http://cancercouncil.com.au).

## 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 if every ache and pain means the cancer is coming back.

Some people say they feel pressure to return to “normal life”, but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

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.

### 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 medicines – even for a short

time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to [beyondblue.org.au](http://beyondblue.org.au) or call **1300 22 4636** to order a fact sheet.

## Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back. Your doctor may want to see you three to four times a year for the first couple of years. This will gradually decrease to twice a year. Your doctor will talk to you about the best follow-up schedule for your situation.

Follow-up appointments may include a physical examination, blood tests, discussion about any new symptoms or late effects of treatment (see page 31), and imaging tests. 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.

If these examinations and tests show that there are no further problems, your appointments will become less frequent. Tell your doctor immediately if you have any health problems or notice new symptoms between check-ups.

## What if Hodgkin lymphoma returns?

For some people, Hodgkin lymphoma does come back after treatment. This is known as a recurrence or relapse. Hodgkin lymphoma that has recurred can still be treated. Most people who have a recurrence will go into remission again.

Further chemotherapy (and, sometimes, radiotherapy) will usually be given to people with recurrent Hodgkin lymphoma. In many cases, people with recurrent Hodgkin lymphoma receive a stem cell transplant to increase the chance of remission (see pages 33–36).



# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in NSW for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

### Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ I found that my support group was a useful, safe place to express my emotions and experiences without having to censor myself to protect the feelings of other people. ” Jan



## Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping. Cancer Council offers support for carers through Cancer Council Online Community ([cancercouncil.com.au/OC](http://cancercouncil.com.au/OC)).

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737.

There are also many groups and organisations that can provide you with information and support. Carers NSW is a statewide organisation specifically for carers. Visit [carersnsw.org.au](http://carersnsw.org.au) or phone 1800 242 636 for more information and resources, including information on respite services and short-term counselling. Oncology social workers can also offer support and referral services to caregivers.

Call Cancer Council 13 11 20 to find out more about carers' services or to request a copy of the *Caring for Someone with Cancer* booklet. You can also download the booklet from [cancercouncil.com.au](http://cancercouncil.com.au).



# Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

## Australian

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Cancer Council NSW .....	<a href="http://cancercouncil.com.au">cancercouncil.com.au</a>
Cancer Australia .....	<a href="http://canceraustralia.gov.au">canceraustralia.gov.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>
Australian Red Cross Blood Service .....	<a href="http://donateblood.com.au">donateblood.com.au</a>
beyondblue.....	<a href="http://beyondblue.org.au">beyondblue.org.au</a>
Carer Gateway.....	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Carers NSW.....	<a href="http://carersnsw.org.au">carersnsw.org.au</a>
Children's Cancer .....	<a href="http://childrenscancer.canceraustralia.gov.au">childrenscancer.canceraustralia.gov.au</a>
Department of Health .....	<a href="http://health.gov.au">health.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>
Radiation Oncology: Targeting Cancer.....	<a href="http://targetingcancer.com.au">targetingcancer.com.au</a>

## International

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American Cancer Society.....	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK.....	<a href="http://cancerresearchuk.org">cancerresearchuk.org</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>
Macmillan Cancer Support (UK).....	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
National Cancer Institute (US) .....	<a href="http://cancer.gov">cancer.gov</a>



## Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about Hodgkin lymphoma and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of Hodgkin lymphoma do I have?
- Where is my Hodgkin lymphoma?
- What stage Hodgkin lymphoma do I have?
- What treatment do you recommend and why?
- Are there other treatment choices for me?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost?
- Will the treatment cause any pain? How will it be managed?
- Will the treatment affect my sex life and fertility?
- When is the best time to have my stem cells collected?
- Are the latest tests and treatments for Hodgkin lymphoma available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the Hodgkin lymphoma comes back, how will I know?
- What are my treatment options if the Hodgkin lymphoma comes back?



# 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 type of transplant where the stem cells or tissues are taken from one person and given 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 remainder of the blood is returned to the body. Apheresis is one of the key steps in a stem cell transplant.

## **autologous transplant**

A type of transplant where stem cells or bone marrow are taken from a person's body and then given 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, which 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 as part of a bone marrow biopsy.

## **cells**

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

## **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**

A computerised tomography scan. This scan uses x-rays to create three-dimensional pictures of the body.

## **cycle**

The time between one chemotherapy treatment session and the next.

**diaphragm**

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

**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 spreads from the lymph nodes to other places in the body.

**granulocyte-colony stimulating factor (G-CSF)**

A growth factor used to stimulate the development of stem cells before collection 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**

Cancer of the lymphatic system. Also called Hodgkin disease.

**immune system**

A network of cells and organs that protects the body against disease and infection.

**immunotherapy**

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

**liver**

A large organ in the top right side of the abdomen. The liver plays an important role in metabolism, digestion, detoxification and removal of substances from the body.

**lymph**

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 tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

**lymph glands**

See lymph nodes.

**lymph nodes**

Small, bean-shaped glands 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 body's tissue fluid (lymph). They are found throughout the body and in a number of organs.

### **MRI scan**

Magnetic resonance imaging scan. It uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

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

The least common type of Hodgkin lymphoma.

### **non-Hodgkin lymphoma**

A cancer of the lymphatic system in which lymphocytes become abnormal and the immune system is less able to fight infections.

### **palliative treatment**

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

### **PET scan**

Positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution to find cancerous areas.

### **platelets**

One of three 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.

### **radiotherapy**

The use of radiation, such as x-rays or gamma rays, to kill or injure cancer cells so they cannot grow and multiply. Also called radiation therapy.

### **recurrence**

The return of a disease after a period of improvement (remission). Also called relapse.

### **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.

### **remission**

When the symptoms and signs 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 produces lymphocytes, filters the blood, and destroys old blood cells, abnormal cells and bacteria.

### **stem cells**

Unspecialised cells from which various types of mature cells can develop. Stem cells are found in the bone marrow.

### stem cell transplant

A treatment in which diseased blood cells are destroyed by high-dose chemotherapy or radiotherapy, 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.

### thymus gland

A part of the lymphatic and immune systems. The thymus gland contains lymphocytes and is where many of these cells mature.

### tissue

A collection of cells that make up part of 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 fluid (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 non-invasive scan that uses soundwaves to create a picture of part of the body. An ultrasound scan can be used to measure the size and position of a tumour.

### white blood cells

One of three types of cells found in the blood. They help fight infection.

### Can't find a word here?

For more cancer-related words, visit:

- [cancerCouncil.com.au/words](http://cancerCouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## References

1. DA Eichenauer et al., "Hodgkin's lymphoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 25 (Supplement 3), 2014, pp. iii70–iii75.
2. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: All cancers combined*, AIHW, Canberra, 2017.
3. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Hodgkin lymphoma*, AIHW, Canberra, 2017.



# 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 Pink Ribbon Fundraising, 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).

*This booklet is funded through the generosity of the people of NSW.*