Understanding Hodgkin’s Disease
A guide for people with cancer, their families and friends.
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The Cancer Council New South Wales
The 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.

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Before commencing any health treatment, always consult your doctor. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor’s or health professional’s advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

The Cancer Council New South Wales
153 Dowling Street
Woolloomooloo NSW 2011

Cancer Council Helpline: 13 11 20
Telephone: (02) 9334 1900
Facsimile: (02) 9334 1741
Email: feedback@nswcc.org.au
Website: www.cancercouncil.com.au
Introduction

This booklet has been prepared to help you understand more about Hodgkin’s disease.

Many people feel understandably shocked and upset when told they have Hodgkin’s disease. We hope this booklet will help you understand how Hodgkin’s disease is diagnosed and treated. We also include information about support services.

We cannot advise you 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 questions you want to ask your doctors or other health carers.

You may like to pass this booklet to your family and friends for their information.

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.

If you’re reading this booklet for someone who doesn’t understand English, contact the Cancer Council Helpline for services available in different languages (see page 44).
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What is cancer?

Cancer is a disease of the body’s cells, which are the body’s basic building blocks. Our bodies constantly make new cells: to help us to grow, to replace worn-out cells, or to heal damaged cells after an injury.

Normally, cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in abnormal blood cells, or a lump called a tumour.

Some benign tumours are precancerous and may progress to cancer if left untreated. Other benign tumours do not develop into cancer.
A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread outside its normal boundary to other parts of the body. A malignant tumour is made up of cancer cells. If it hasn’t invaded nearby tissue, it is known as a cancer in-situ (or carcinoma in-situ). If the tumour has invaded surrounding tissue, it is called invasive cancer. An invasive cancer that has not spread to other parts of the body is called primary cancer.

With cancers that affect the blood and bone marrow, abnormal cells multiply in such a way that they crowd the bone marrow and reduce its ability to make normal blood cells. Sometimes the abnormal cells also clump together to form a tumour.

If you have Hodgkin’s disease, the cancer cells usually affect and enlarge your lymph nodes, behaving like a primary cancer at more than one lymph node site.

If cells move away from the original (primary) cancer and invade the bone marrow, other body tissues and organs, it is called a secondary cancer or metastasis.
Hodgkin’s disease is cancer of the lymphatic system.

The lymphatic system is part of the immune system, which protects the body against disease and infection. The lymphatic system comprises a network of thin tubes (lymph vessels) found all over the body.
Lymph vessels carry a clear fluid called lymph. This fluid originates in the tissues and is emptied into the bloodstream. Lymph contains white blood cells called lymphocytes, which help fight infection.

A network of small, bean-shaped structures called lymph nodes (glands) are located along the lymph vessels. Lymph nodes trap germs and bacteria that cause infection. They are found in places such as the neck, chest, abdomen, groin and underarms.

When germs are trapped in the lymph nodes, the nodes become swollen. This is a sign that your body is fighting the infection. For example, the glands in your neck swell when you have a sore throat.

Other parts of the lymphatic system include:

- **spleen**: found on the left side of the abdomen, under the ribs. It contains lymphocytes, filters waste products from the blood and destroys old blood cells.
- **thymus**: found inside the rib cage, behind the breastbone. It contains lymphocytes and helps filter waste products from the blood.
- **tonsils**: a collection of lymphoid tissue at the back of the mouth, at the beginning of the throat (oropharynx).
- **bone marrow**: the soft, spongy material inside bones. Bone marrow makes three types of blood cells: oxygen-carrying red cells, infection-fighting white cells, and cells called platelets, which help the blood to clot.
What is Hodgkin’s disease?

Hodgkin’s disease is a type of lymphoma, which is a general term for a cancer that begins in the lymph tissue.

When you have Hodgkin’s disease, your lymphocytes become damaged. They grow and multiply uncontrollably, which causes your lymph nodes to become enlarged and form painless lumps called tumours. As damaged lymphocytes replace normal lymphocytes, your immune system becomes less able to fight infection.

Hodgkin’s disease may occur in a single lymph node, a group of lymph nodes, or in an organ such as the liver or spleen. Sometimes, Hodgkin’s disease can appear in several parts of the body at the same time.

Non-Hodgkin’s lymphoma

There are two types of lymphoma: Hodgkin’s disease and non-Hodgkin’s lymphoma.

The difference between Hodgkin’s disease and non-Hodgkin’s lymphoma is a type of cancer cell. In Hodgkin’s disease, tumours contain large cells called Reed-Sternberg cells. These cells are not found in non-Hodgkin’s lymphoma.

This booklet contains information about Hodgkin’s disease. For more information about non-Hodgkin’s lymphoma call the Cancer Council Helpline on 13 11 20 for a free copy of "Understanding non-Hodgkin’s Lymphoma."
Causes of Hodgkin’s disease

The cause of Hodgkin’s disease is unknown. Researchers think a combination of factors from a person’s genes and from their environment may cause Hodgkin’s disease.

Researchers know that the disease does not run in families and is not contagious.

What are the symptoms?

The most common first symptom of Hodgkin’s disease is a painless swollen lymph gland in your neck, under your arm, or in your groin.

Other symptoms may include:
- unexplained fevers
- sweating, particularly at night
- weight loss
- tiredness.

These symptoms are common to many conditions, such as the flu or a virus. Most people with these symptoms do not have Hodgkin’s disease. However, if you have these symptoms and there is no obvious cause, such as an infection, see your general practitioner (GP).

How common is it?

About 11% of all lymphomas are types of Hodgkin’s disease.

According to the Cancer Institute NSW, 174 people (84 men and 90 women) in NSW were diagnosed with Hodgkin’s disease in 2005. Hodgkin’s disease usually develops in people between the ages of 15 to 29 and 60 to 70.
Diagnosis

If your doctor suspects that you have Hodgkin’s disease, you will have a physical examination. In this exam, your doctor will feel the lymph nodes in your neck, underarms or groin for signs of swelling and feel your abdomen to check for swollen organs.

You may also have a blood test to check your bone marrow, kidney and liver function.

Biopsy

A diagnosis of Hodgkin’s disease is made by removing some tissue and sending it to the laboratory for examination under a microscope. This is called a biopsy.

Biopsies can be done in different ways:

- **Excision biopsy of a lymph node (tumour):** If the lymph node is near the surface of your skin, your doctor will give you a local anaesthetic and remove the lymph node by cutting into your skin. However, if the lymph node is located deeper under your skin, it will be removed while you are under a general anaesthetic. You will have some stitches while your wound heals, and you may be in hospital for a few days.

- **Needle biopsy:** In this type of biopsy, a needle is inserted into the lymph node to remove a small amount of tissue. In some cases, however, a needle biopsy does not provide enough tissue to make a diagnosis, and an excision biopsy is also required.

It will probably take about one week for your biopsy results to be ready. This waiting period can be an anxious time and it may help to talk things over with a supportive friend, relative or health professional.
Further tests

If the biopsy shows you have Hodgkin’s disease, a number of other tests will be done. You may have one of these tests or a combination of several tests.

The following tests will show if the Hodgkin’s disease has spread to other parts of your body. The test results will also help the doctor to determine how much cancer is in your body. This is called staging (see page 16). Staging your cancer will help your doctor recommend the best treatment for you.

Blood tests

Blood samples will be taken regularly 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), fighting infection (white) and helping your blood clot (platelets). If your blood count is low, it may indicate that Hodgkin’s disease has spread to your bone marrow.

Blood is also taken to see how well your kidneys and liver are working. These organs sometimes do not work properly if Hodgkin’s disease is present. Other blood tests may be done to help your doctor determine how active the Hodgkin’s disease is.
Chest x-ray

An x-ray of the chest may be taken to check if the Hodgkin’s disease has spread to the lymph nodes in your chest or lungs.

Bone marrow biopsy

A bone marrow biopsy is done to determine if Hodgkin’s disease is in the soft spongy material inside your bones that is responsible for the creation of your blood cells (bone marrow).

You will lie still while you receive a general or a local anaesthetic to your pelvis or breastbone region, where the biopsy will be performed. The health professional performing the biopsy will insert a needle into your bone to remove a small piece of bone marrow. It usually only takes a few minutes to obtain a sample, but you may feel some pressure or discomfort.

Some people feel some pain after their bone marrow biopsy. Ask a member of your health care team about pain-relieving medication if you are uncomfortable. You may be given some medication (short-acting sedatives) so you are able to rest and recover.

The bone marrow biopsy felt strange and uncomfortable and took longer than I expected. But I had taken pain-killers so it did not hurt.
PET scan

A positron emission tomography (PET) scan is a specialised imaging test, which is only available at some hospitals.

Before the scan, you will be injected with a radioactive glucose solution. You will be sedated or asked to sit quietly for about 30 to 90 minutes while the glucose solution circulates through your body, then your body will be scanned for high levels of radioactive glucose. Active cells, such as cancer cells, have an increased absorption of this solution.

A PET scan is usually performed on an outpatient basis, however the preparation and scan will take several hours.

CT scan

A computerised tomography (CT) scan is a procedure that uses x-ray beams to take pictures of the inside of your body. Unlike a standard x-ray, which takes a single picture, a CT scan uses a computer to compile many pictures of areas of your body.

You may have a special dye injected into your veins before the scan. This injection will help make the scan pictures clearer. It may make you feel flushed or hot for a few minutes. Rarely, more serious reactions occur, such as breathing difficulties or low blood pressure.
You will be asked to lie still on a table while the CT scanner, which is large and round like a doughnut, slowly rotates around you.

This painless test takes between 30 to 60 minutes, and you will be able to go home when the scan is complete.

**MRI scan**

A magnetic resonance imaging (MRI) scan uses a combination of magnetism and radio waves to build up detailed cross-section pictures of the body. This test involves lying on a couch in a metal cylinder, which is a large and powerful magnet.

As with a CT scan, special dye may be injected into your veins before the scan.

Some people feel anxious lying in the narrow metal cylinder when they are having an MRI. Talk to your health care team before the scan if you are claustrophobic. It may be helpful to take a mild sedative or talk to the person operating the MRI machine through an intercom.

Though the MRI scanner can feel tightly enclosed and noisy, the test is painless and is usually complete in about one hour. You will be able to go home when your scan is complete.

People who have a pacemaker or certain other metallic objects in their body will not be able to have an MRI due to the effect of the magnet.
**Gallium scan**

In a gallium scan, a weak radioactive substance called gallium is injected into a vein in your arm. Over two to three days, the gallium accumulates in areas of enlarged, abnormal lymph nodes. The gallium is painless and having it in your body will not harm you.

After the gallium has circulated through your body, your doctor will view your body through a camera and perform scans of your body. This will help to determine where the Hodgkin’s disease has spread.

**Ultrasound**

An ultrasound uses soundwaves to create a picture of your internal organs. This can allow your doctor to check for any unusual lymph activity.

A gel is spread over your skin and a small device called a transducer is passed over the area. The transducer creates soundwaves and receives echoes. A computer creates a picture based on the echoes produced when soundwaves meet something dense, such as an organ or tumour.

An ultrasound will only take a few minutes, so it is usually performed as an outpatient scan.
Stages of Hodgkin’s disease

After the biopsy and the results of further tests, one of the following stages will be used to describe the Hodgkin’s disease:

- **Stage 1:** Cancer is found in only one lymph node area or in one area outside the lymph nodes.
- **Stage 2:** Cancer is found in two or more lymph node areas on the same side of the diaphragm (the sheet of muscle beneath the lungs).
- **Stage 3:** Cancer is found in the lymph nodes above and below the diaphragm.
- **Stage 4:** Cancer is found in the lymph nodes and in other areas of the body, such as the liver, lungs or bones.

Your doctor may describe the stage of your cancer as either subgroup A (no symptoms) or subgroup B (symptoms such as an unexplained fever, weight loss and night sweats).

Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis with your doctor, but it is not possible for any doctor to give you a 100% accurate prediction on the course of the illness. Test results, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as age, fitness and your medical history are all important factors in assessing your prognosis.

Most people who receive treatment for Hodgkin’s disease will achieve long-term or permanent remission, or control of the disease for years. During periods of remission, you will require regular checkups to ensure you are still healthy.

Hodgkin’s disease may come back (relapse) in some cases. See page 36 for more information about treatment for relapse.
Your GP will probably arrange the first tests to assess your symptoms. This can be a worrying and tiring time, especially if you need several tests. If these tests do not rule out cancer, you will usually be referred to a haematologist, who will arrange further tests and advise you about your treatment options.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team. The team may include:

- **haematologist**: diagnoses and treats diseases of the bone marrow, blood and lymphatic system
- **surgeon**: diagnoses Hodgkin’s disease by removing an enlarged lymph node
- **cancer care coordinator or clinical nurse consultant**: coordinates your care, supports you throughout treatment and answers your questions
- **medical oncologist**: prescribes and coordinates chemotherapy
- **radiation oncologist**: prescribes and coordinates radiotherapy
- **radiation therapist**: operates the radiotherapy machine
- **nurses**: administer chemotherapy and other medications, and support and assist you through all stages of your diagnosis and treatment
- **dietitian**: supports and educates patients about optimal nutrition and diet during treatment and recovery
- **social worker, psychologist, occupational therapist and pastoral worker**: advise you on support services, help you to resume normal activities, and provide emotional support.
Treatment

Chemotherapy and radiotherapy are the main treatments for Hodgkin’s disease. These are often combined to reduce side effects and improve treatment outcome.

Some people – usually those with more advanced or relapsed cases of Hodgkin’s disease – receive peripheral stem cell or bone marrow transplants. Transplants are described in more detail on pages 23 to 25.

Chemotherapy

Chemotherapy uses cytotoxic drugs, which kill or slow the growth of cancer cells. It is often used to treat early-stage lymphomas, however it can also be used to treat advanced Hodgkin’s disease.

Chemotherapy is usually given through a needle inserted into a vein (intravenously), by specialised nurses and under the guidance of your specialist. Less commonly, chemotherapy is given orally in tablet form.

One common type of chemotherapy for Hodgkin’s disease is repeated on one day every two weeks. Other types of chemotherapy are given at different intervals. For example, you might have treatment for a few days and then have a rest period. The treatment you receive depends on your circumstances.

As you have treatment, your doctor or nurse will take blood samples to check that your resistance to infection is not too low (see page 20). If your red blood cell or platelet counts become too low, you may require a transfusion.

Ask your doctor before taking any other medications, such as vitamin supplements or vaccines. Other medication may affect how chemotherapy works in your body.
Side effects

Chemotherapy drugs affect the healthy fast-dividing cells in your body in addition to the cancerous cells. As a result, you may experience side effects like an upset stomach, nausea, vomiting, mouth ulcers, headaches, hair loss, bowel problems and fatigue.

These side effects are temporary and there are many ways to prevent or reduce them. Make note of any side effects you experience and tell your doctor about them. They may reduce the dosage of the drug you are taking, prescribe a break in your treatment, change the kind of treatment you are having, or give you medication to relieve your side effects.

Chemotherapy may affect sexual organs and functioning in both men and women. This may have a temporary or permanent effect on your ability to have children (fertility). It is best to talk to your doctor about these effects as early as possible.

For more information about chemotherapy and its side effects, refer to the *Understanding Chemotherapy, Sexuality for Women with Cancer* and *Sexuality for Men with Cancer* booklets, which are available from the Cancer Council. Call the Helpline on 13 11 20 for free copies.
When you have chemotherapy, colds and flu may be easier to catch and harder to shake off, and scratches and cuts may get infected more easily. This is because the chemotherapy drugs have lowered your body’s ability to fight infection (reduced your white blood cell count).

You may want to ask people close to you to have a flu shot, if they are able and willing to do so. You should also ask family or friends with a cold or the flu to wait until they are well before visiting. Of course, this is not practical for people you live with, so use your commonsense and try to avoid close contact with people until they are well.

Keep a thermometer at home so you can check your temperature. Contact your doctor or hospital immediately if any of these problems occur:

- a fever over 38°C
- chills or constant shivering
- sweating, especially at night
- a burning feeling 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 movements
- prolonged faintness and a rapid heartbeat.
Radiotherapy

Radiotherapy is the use of high-energy x-rays or electrons to kill or damage cancer cells. Your treatment will be carefully planned to do as little harm as possible to your healthy cells.

Radiotherapy is usually given as multiple small doses over several days or weeks to maximise the effect of treatment and reduce side effects. The length of treatment will depend on the size and type of cancer and your general health.

You will lie alone in a room under a large machine that delivers x-ray beams to the treatment area. Each treatment session only takes a few minutes once started, but it can take longer to set up the equipment. Your first radiotherapy treatment will take between one and three hours, as you will see the radiation oncologist, have blood tests and have the machine set up properly.

Side effects

Radiotherapy can cause side effects because it damages normal cells near the cancer. Most side effects are temporary and there are ways to reduce your discomfort.

The most common side effects of radiotherapy are tiredness and drowsiness. Other side effects will depend on the part of the body being treated. Radiotherapy to the abdomen may cause an upset stomach and diarrhoea. Radiotherapy to the neck can make your mouth and throat sore and affect your sense of taste. Occasionally, radiotherapy can cause temporary reddening of the skin at the site of therapy.

For suggestions on managing these side effects and other side effects you may experience, see the Cancer Council’s booklet, Understanding Radiotherapy.
Late effects of treatment

Advances in treatment and early detection mean that it is possible for doctors to achieve remission for most Hodgkin’s disease patients.

Unfortunately, the success of radiotherapy and chemotherapy treatments may have unintended side effects. Some side effects can occur several months or years after radiotherapy or chemotherapy has ended, so they are known as late effects.

Radiotherapy can increase your risk of developing other types of cancer, especially near areas where treatment was given. Treatment to the chest may increase the risk of breast cancer in young women. Another late effect of radiotherapy to the neck may be an underactive thyroid gland (hypothyroidism).

Some chemotherapy drugs may also increase the chance of developing a second cancer later in life.

These possible late effects should be discussed with your doctor before starting your treatment. Commonly, a combination of chemotherapy drugs less likely to cause late effects is used.

It may be hard to accept that the effects of Hodgkin’s disease on your life do not end when your treatment is over and you have no symptoms of cancer (remission). However, being aware of possible late effects means you can take precautions such as having regular follow-up tests.

Researchers are trying to find ways to minimise the late effects of treatment while maintaining the high remission rate of Hodgkin’s disease.
Stem cell or bone marrow harvest and transplantation

A transplant of stem cells is sometimes used for the treatment of lymphoma. Stem cells are early-stage cells from which other cells develop. Most stem cells are found in the bone marrow. However, small amounts of stem cells are found in your blood (these are called peripheral stem cells).

There are two types of transplants. You may receive either type, depending on your circumstances:

1. **Autologous transplant**: Your own stem cells are extracted from your body, stored, and re-injected after chemotherapy or radiotherapy treatment.

2. **Allogeneic transplant**: Stem cells are collected from a donor and injected into your body after chemotherapy or radiotherapy treatment.

Before either type of transplant, you will receive high doses of chemotherapy. This will clear your body of any remaining Hodgkin’s disease cells and your bone marrow of stem cells.

When you receive your transplant, the stem cells re-populate your bone marrow and blood cells.
A month on... After chemo, the stem cells are thawed and put back.

First, a drug helps stem cells multiply and release into the blood.

Several days later, some blood is taken out.

The stem cells are separated, processed and frozen. Your other blood cells are returned to you.

This is a simple overview of a transplant process. Your case may be different.
Side effects

After stem cell or bone marrow transplantation, you may be in hospital for three to six weeks. The length of your hospital stay will depend on the type of transplant (allogeneic or autologous) and the side effects you experience.

Many transplantation side effects are similar to the side effects of chemotherapy, but more severe. These include an increased chance of bruising, bleeding and feeling nauseous and fatigued. You may also develop infections, mouth ulcers and diarrhoea. Talk to your doctor or nurses about how to manage these side effects.

If you receive an allogeneic bone marrow transplant, you will be at risk for a serious complication called graft-versus-host disease (GVHD). GVHD occurs when immune cells in the donor’s transplanted tissue (graft) attack your body tissue because it is recognised as foreign.

Your doctors will give you drugs to suppress your immune system and prevent your body from rejecting the graft. While you are in hospital, your health care team will also limit your exposure to common germs (such as colds and flu), because these infections can be life threatening when your immune system is suppressed.

It is possible to get GVHD immediately following your transplant or years afterward. If you experience symptoms such as abdominal pain, vomiting or a skin rash, see your doctor immediately.
Palliative treatment

Palliative treatment is particularly important for people with advanced cancer. It helps improve people’s quality of life by alleviating symptoms of cancer, without trying to cure the disease. Often treatment is concerned with pain relief and stopping the spread of cancer, but it can also involve the management of other physical and emotional problems. Treatment may include radiotherapy, chemotherapy or other medication.

For more information on palliative treatment or advanced cancer, call the Helpline for free copies of *Understanding Palliative Care* or *Living with Advanced Cancer*, or view them online at www.cancercouncil.com.au.
Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast that you don’t have time to think things through, but there is usually time for you to consider what sort of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed with information, others feel they don’t have enough. You need to make sure you understand enough about your illness, the treatment and side effects to make your own decisions.

If you are offered a choice of treatments, you will need to weigh the advantages and disadvantages of each treatment. If only one type of treatment is recommended, ask your doctor to explain why other choices have not been offered.

Some people with more advanced cancer will choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects so they have the best possible quality of life. Some people choose not to have treatment to get rid of the cancer, but instead optimise their physical and emotional well-being by managing their symptoms.

You always have the right to find out what a suggested treatment means for you, and the right to accept or refuse it.
Decision-making steps

1. Take the time to consider all treatment options.

2. Weigh up the advantages and disadvantages of each treatment.

3. Consider how important each side effect is to you – particularly those that affect your lifestyle. If you have a partner, discuss the side effects with them.

4. If only one type of treatment is recommended, ask your doctor if other treatment choices are available.

5. Find out more about the treatment choices offered to you – speak to your doctor, consider getting a second opinion, look at the recommended Internet sites on pages 46 to 47, talk to your family and friends and to people who have received these treatments.

6. If you are not happy with the information you are given – or how it is given – tell the doctor about your concerns, or seek a second opinion.
Talking with doctors

When your doctor first tells you that you have Hodgkin’s disease, it is very stressful and you may not remember very much. It is often difficult to take everything in, so you may want to see the doctor a few times before deciding on treatment. Your doctor may use medical terms you don’t understand; it’s okay to ask your doctor to explain something again. You can also check a word’s meaning in the glossary at the end of this booklet.

Before you see the doctor, it may help to write down your questions – see the list of suggested questions on page 49. Taking notes during the session or recording the discussion can also 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.

I took a friend with me for support to the second appointment. It was like a dream where I just said ‘yes, yes, yes’ and luckily my friend wrote down all the information.
Talking with others

Once you have discussed treatment options with your doctor, you may want to talk them over with family or friends, nursing staff, the hospital social worker or chaplain, your own religious or spiritual adviser, a cancer support group or the Cancer Council Helpline on 13 11 20. Talking it over can help sort out the right course of action for you.

A second opinion

You may want to get a second opinion from another specialist. Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.

A second opinion can be a valuable part of your decision-making process. It can confirm or clarify your doctor’s recommended treatment plan and reassure you that you have explored all of your options. A second specialist can also answer any questions you may still have.

Your original specialist or family doctor can refer you to another specialist and you can ask for your initial results to be sent to the second-opinion doctor.

You may later decide you would prefer to be treated by the doctor who provided the second opinion, and you are within your rights to make this choice.

You can ask for a second opinion even if you have already started treatment or still want to be treated by your first doctor.
Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments and see if they are better than current treatments.

Before deciding whether or not to join the trial, you may wish to ask your doctor:

• What treatments are being tested and why?
• What tests are involved?
• What are the possible risks or side effects?
• How long will the trial last?
• Will I need to go into hospital for treatment?
• What will I do if problems occur while I am in the trial?
• Has an independent ethics committee approved the trial?

If you are unsure about joining a clinical trial, ask for a second opinion from an independent specialist.

If you decide to join a randomised clinical trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being in a trial gives you important rights. You have the right to withdraw at any time. Doing so will not jeopardise your treatment for cancer.

For more information about clinical trials – and how to find a trial that may be suitable for you – call the Helpline for a free copy of Understanding Clinical Trials.
Looking after yourself

When you find out you have cancer and while you are undergoing treatment, your body is put through a great deal of physical and emotional strain. Taking steps to enhance your well-being at this time will help you adapt to the stress that you are facing. Nurturing your body and mind by eating nourishing food, doing some enjoyable physical activity, and taking some time out to relax can help you to feel more balanced and improve your vitality.

Healthy eating

Eating nutritious food will help you keep as well as possible and cope with the cancer and treatment side effects. Depending on your treatment, you may have special dietary needs. A dietitian can help to plan the best foods for your situation – ones that you find tempting, easy to eat and nutritious.

The Cancer Council Helpline can send you information on nutrition during and after cancer treatment. Call the Helpline on 13 11 20 for free copies of Food and Cancer and After Your Cancer Treatment: a guide for eating well and being active.
Being active

You will probably find it helpful to stay active and to exercise regularly if you can. Physical activity – even if gentle or for a short duration – helps to improve circulation, reduce tiredness, decrease joint or muscle pain, and elevate mood. The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises.

Start by making small changes to your daily activities, such as walking to the shops. Even gardening can be beneficial. If you want to do more vigorous exercise or weight-bearing exercise, ask your doctor what is best for you.

Relaxation techniques

Some people find relaxation or meditation helps them feel better by releasing tension and anxiety. Often, relaxation exercises can also help reduce pain and increase energy levels. The hospital social worker or nurse will know whether the hospital or a community health centre runs any programs.

You may also enjoy exploring relaxation techniques in the comfort of your own home using audiovisual material such as CDs or DVDs. Contact your local library or the Cancer Council Helpline to access these resources.
Complementary therapies

Complementary therapies may help you enhance your general well-being and cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, including acupuncture, massage, hypnotherapy, relaxation, yoga, herbal medicine and nutrition. While some cancer treatment centres offer complementary therapies as part of their services, you may have to go to a private practitioner. Ask what’s available at your hospital.

Be sure to let your doctor know about any complementary therapies you are using or thinking about trying. This is important, as some therapies may not be appropriate, depending on your conventional treatment. For example, some herbs and nutritional supplements may interact with your medication, resulting in harmful side effects. Massage and exercise therapies may also need to be modified to accommodate the changes in your body.

Call the Helpline for a copy of the Cancer Council’s latest publication on complementary therapies.
Life after treatment

Many people find it helps to give themselves time to recover from treatment. You will find you must cope with both physical and emotional changes, and you will have to continue to have regular checkups to make sure your Hodgkin’s disease does not return (see page 36).

You need time to get your strength back. If you’re responsible for the house, you’ll need some help for a while. If you work, you’ll need to ease back into it slowly, rather than rushing back the week after leaving hospital.

You might have to remind your family and friends that for a while you won’t be fit enough to do all your usual activities.

After treatment is over it is common for people to feel anxious rather than more secure. While you were having treatment, you were busy with appointments and now you are facing life again with an uncertain future. Adjusting to life after cancer can be difficult if people around you expect your life to return to the way it was before you were diagnosed.

Everyone will eventually re-establish their daily routine, but it will be at their own pace. It may take some time to balance the need for regular checkups with resuming day-to-day activities and making plans for the future. Talking to someone who has had Hodgkin’s disease can help you deal with this uncertainty. For more information see page 43.
Will the cancer come back?

After treatment finishes, you might feel pressure to get back to ‘normal life’. Many people feel that life will never be the same after an experience with cancer – indeed, some people have even reported that they have a new perspective on life and that they see things with a new clarity.

Still, fear of Hodgkin’s disease returning can feel like a shadow on your life. You might worry about every ache and pain and wonder if it is the cancer coming back. It might reassure you to talk to your doctor and ask about what to expect if the cancer were to return.

This is a difficult time and it will take time to readjust. If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation for things that previously gave you pleasure, talk to your doctor. You might be clinically depressed and there are ways that your doctor can help you.

If the Hodgkin’s disease relapses

While many people achieve long-lasting or permanent remission following their treatment, sometimes Hodgkin’s disease does come back after a period of remission. This is called a relapse.

In most cases, Hodgkin’s disease that has relapsed can still be treated, and you may achieve remission again. Further chemotherapy (and, possibly, radiotherapy) will usually be given. Sometimes people with advanced or relapsed Hodgkin’s disease receive a stem cell or bone marrow transplant (see pages 23 to 25). Your doctor will talk to you about your treatment options.
Strengthening your relationships

The strong emotions you experience as a result of cancer may affect your relationships with people close to you. Your experiences can cause you to develop a new outlook on your values, priorities and life in general. It may help to share those thoughts and feelings with your family, friends and work colleagues.

It may be uncomfortable to talk about your feelings; take your time and approach others when you are ready. You may feel relieved when you have talked to them. People usually appreciate insight into how you are feeling and guidance on how they can best support you during and after treatment. This open and honest approach can strengthen your relationships.

While you are giving yourself time to adjust to life after cancer, remember to do the same for your friends and family. Everyone will react in a different way – by putting on a happy face, playing down your anxiety, or even ignoring you. They are also adjusting to changes in their own way. If someone’s behaviour upsets you, it will probably help to have a discussion about how you both feel about the situation.
Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is more common if your body has changed physically, but even if it has not, you may still be affected by lowered self-esteem.

Give yourself time to adapt to these changes and try not to focus solely on the parts of you that have changed. Seeing yourself as a whole person (your body, mind and personality) can help to increase your self-esteem. You may eventually adjust to and come to accept any physical changes.

For practical suggestions on dealing with hair loss, weight changes and other physical changes, call the Helpline on 13 11 20.

Look Good…Feel Better is a program that helps people restore their self-esteem by managing appearance-related side effects. Call 1800 650 960 or visit www.lgfb.org.au.
Sexuality, intimacy and cancer

The role that sexuality and intimacy play in people’s lives is ever changing and depends on one’s age, environment, health, relationships, culture, beliefs and interest. As individuals, people not only have different ways of expressing and defining sexuality and intimacy, but they also place their own importance on these needs.

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as your treatment and its side effects, the way you and your partner communicate, and your self-confidence. Knowing the potential challenges, such as a change in libido, and addressing them if they affect you personally will help you overcome or adjust to these changes.

Sexual intercourse may not always be possible, but closeness and sharing are vital to a healthy relationship.

More information about sexuality for both men and women is available. Call the Helpline for a copy of the Cancer Council’s sexuality booklets.

If you have had chemotherapy or radiotherapy to the pelvic region, your doctor may recommend you use contraceptives or abstain from having sex for a certain period of time following treatment.
Seeking support

When you are first diagnosed with cancer, it is normal to experience a range of emotions, such as fear, sadness, depression, anger or frustration. If anxiety or depression is ongoing or severe, tell your doctor about it as counselling or medication can help.

It may help to talk about your feelings with others. Your partner, family members and friends are a good source of support or you might prefer to talk to:
- members of your treatment team
- a hospital counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 43
- the Cancer Council Helpline.

If you have children, the prospect of telling them you have cancer can be frightening and unsettling. The Cancer Council booklet *When a Parent Has Cancer: how to talk to your kids* can help you prepare for this difficult conversation.

You may find that your friends and family don’t know what to say to you. In time, you may feel able to approach your friends directly and tell them what you need. Some people prefer to ask a family member or a friend to talk with others and coordinate any offers of help.

Some people may feel so uncomfortable that they avoid you. They may expect you to ‘lead the way’ and tell them what you need. This can be difficult to handle and can make you feel lonely.

The Cancer Council’s booklet *Emotions and Cancer* may help at this stressful time. Ring 13 11 20 for a copy or download it from the Cancer Council’s website, www.cancercouncil.com.au.
Practical and financial help

A serious illness often causes practical and financial difficulties. You don’t need to face these alone.

Many services are available to help:

- Financial assistance, through benefits and pensions, can help pay for the cost of prescription medicines and for travel to medical appointments.

- Home nursing care is available through community nursing services or through the local palliative care services.

- Meals on Wheels, home care services, aids and appliances can make life easier.

To find out more, contact the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline.
Understanding Cancer program

If you want to find out more about cancer and how to cope with it, you may find the Cancer Council’s Understanding Cancer program helpful. The program offers practical information and discussions about many of the issues people experience after a diagnosis of cancer. Topics covered include: what cancer is, cancer symptoms and side effects, treatment, palliative care, diet, exercise and complementary therapies. Courses are held frequently at hospitals and community organisations throughout NSW. Call the Helpline to find out more.

Being able to talk with someone who has experienced cancer is the most marvellous feeling. With that person I can be completely honest with my feelings and fears.
Talk to someone who’s been there

Getting in touch with other people who have been through a similar experience to you can be very beneficial. There are many ways you can get in contact with others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Support services are available for patients, carers and family members. They include:

- face-to-face support groups, which are often held in community centres or hospitals
- tumour- or situation-specific telephone support groups, which are facilitated by trained counsellors
- online discussion forums where people can connect with each other any time
- Cancer Council Connect, a program that matches you with a volunteer who has been through a similar cancer experience, and who understands how you’re feeling.

Ask your nurse or social worker to tell you about support groups in your area. Go to www.cancercouncil.com.au or call the Helpline to access the Cancer Services Directory, join an online discussion and find out how you can connect with others.
The Cancer Council Helpline 13 11 20
Monday to Friday 9am to 5pm

The Cancer Council Helpline is a telephone information and support service provided by the Cancer Council NSW for people affected by cancer.

For the cost of a local call, you can talk about your concerns and needs confidentially with oncology health professionals. Helpline consultants can send you written information and put you in touch with appropriate services in your area. You can also request services in languages other than English.

You can call the Cancer Council Helpline, Monday to Friday, 9am to 5pm. If calling outside business hours, you can leave a message and your call will be returned the next business day.

If you have difficulty communicating over the phone, contact the National Relay Service, a Government initiative to assist people who are hearing and/or speech impaired (www.relayservice.com.au). This service will help you to communicate with a Cancer Council Helpline consultant.
Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be very stressful, especially when the person you are looking after is someone you love very much. Look after yourself during this time. 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 are open to carers as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping.

There are several support services that can help you in your caring role, such as Home Help, Meals on Wheels or visiting nurses. There are also many organisations and groups that can provide you with information and support, such as Carers NSW. Phone 1800 242 636 to talk about your needs, or visit www.carersnsw.asn.au.

Call the Cancer Council Helpline to find out more about different services or to obtain a free copy of the Caring for Someone with Cancer booklet.

Bone marrow and blood stem cell donation

One way people can offer indirect support to someone with Hodgkin’s disease is by becoming a bone marrow or blood stem cell donor. Though it is difficult to find a match between unrelated donors and recipients, allogeneic bone marrow transplants are becoming more common.

The more volunteer donors who are available, the better the chance that a patient will have the opportunity to receive a transplant. See the Australian Bone Marrow Donor Registry website on www.abmdr.org.au to learn more.
Further resources

Information on the Internet

The Internet can be a useful source of information, although not all websites are reliable. The websites listed in this section are good sources of reliable information.

Australian

The Cancer Council NSW ............... www.cancercouncil.com.au
The Cancer Council Australia ................. www.cancer.org.au
Cancer Institute NSW .................. www.cancerinstitute.org.au
Health Insite – an Australian Government initiative ......................... www.healthinsite.gov.au
Commonwealth Department of Health and Ageing .............................. www.health.gov.au
NSW Health .................................. www.health.nsw.gov.au
Arrow Bone Marrow Transplant Foundation ................... www.arrow.org.au
Bone Marrow Transplant Network NSW .......................... www.bmtnsw.com.au
Australian Bone Marrow Donor Registry ............................... www.abmdr.org.au
Australian Red Cross Blood Service ............................. www.donateblood.com.au
The Leukaemia Foundation ................... www.leukaemia.org.au
                                         www.talkbloodcancer.com
Lymphoma Support & Research Association .................. www.lymphoma.org.au
Cancer information library

Following a cancer diagnosis, many people would like to access information about new types of treatment, the latest research findings, and stories about how other people have coped.

The Cancer Council’s library has a wealth of information on these topics. There are more than 3,000 resources in the collection, including books, videos, DVDs and a large range of current cancer medical journals.

You can visit the library at 153 Dowling Street, Woolloomooloo (9am-5pm Monday-Friday), borrow by post or ask your local librarian to organise an inter-library loan. Contact the librarian on 13 11 20 or email library@nswcc.org.au.
### Related publications

You might also find the following publications relevant:

- *Emotions and Cancer*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Sexuality for Men with Cancer*
- *Sexuality for Women with Cancer*
- *Understanding Palliative Care*
- *Living with Advanced Cancer*
- *Understanding Clinical Trials*
- *When a Parent Has Cancer: how to talk to your kids*
- *Caring for Someone with Cancer*
- *Food and Cancer*
- *After Your Cancer Treatment: a guide to eating well and being active.*

Call the Helpline on 13 11 20 for free copies of any of these Cancer Council booklets, or download them from our website, [www.cancercouncil.com.au/cancerinformation](http://www.cancercouncil.com.au/cancerinformation).
Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your illness and treatment. If your doctor gives you answers that you don’t understand, it is okay to ask for clarification.

1. What type of Hodgkin’s disease do I have?
2. How extensive is it (what is the stage)?
3. What treatment do you recommend and why?
4. What are the risks and possible side effects of each treatment?
5. How long will treatment take? How much will it affect what I can do?
6. How much will treatment cost?
7. Will I have a lot of pain with the treatment? What will be done about this?
8. Will I have to stay in hospital?
9. Are there other treatment choices for me? If not, why not?
10. Are the latest tests and treatments for my type of cancer available in this hospital?
11. Are there any clinical trials of new treatments?
12. Will the treatment affect my sex life and fertility?
13. How frequently will I have checkups?
14. Are there any complementary therapies that might help me?
Glossary

**abdomen**
The part of the body that includes the stomach, intestine, liver, bladder and kidneys. It is located between the ribs and hips.

**allogeneic transplantation**
A transplant where the cells or tissues are taken from one person and given to another.

**anaesthetic**
A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of body; a general anaesthetic causes a person to lose consciousness for a period of time.

**autologous transplantation**
A transplant where the cells or tissues are taken from a person’s body and reimplanted into the same person’s body.

**benign**
Not cancerous or malignant.

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

**blood**
A watery body fluid that flows through the circulatory system. Blood comprises plasma, red blood cells, white blood cells and platelets.

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

**bone marrow**
The soft, spongy material found inside bones. Bone marrow produces red blood cells, white blood cells and platelets.
bone marrow transplantation
A procedure to replace bone marrow destroyed by high doses of chemotherapy treatment with healthy bone marrow.

chemotherapy
The use of cytotoxic drugs, which kill cancerous cells or slow their growth, to treat cancer.

CT scan
A computerised tomography scan. This scan uses x-rays to build a picture of the body.

diaphragm
A thin muscle under the lungs and heart that separates the chest from the abdomen.

enema
The injection of liquid into the intestines via the anus.

erythrocytes
Red blood cells.

graft-versus-host disease
Also known as GVHD. A complication of allogeneic bone marrow transplantation in which immune cells in the transplanted tissue (graft) attack the cells in the recipient’s body.

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

immune cells
White blood cells (leucocytes).

Hodgkin’s disease
A type of lymphoma.
late effects
Side effects of cancer treatment that occur several months or years after treatment has been completed.

leucocytes
White blood cells. These cells fight infection.

lymph
A clear fluid that circulates around the body through the lymphatic system, carrying cells that fight infection.

lymph nodes
Also called lymph glands. Small, bean-shaped masses of lymph cells scattered across the lymphatic system. Lymph nodes, which are located in the neck, armpit, groin and abdomen, collect and destroy bacteria and viruses.

lymph vessels
Thin tubes that carry lymph fluid all over the body.

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. The lymphatic system is part of the body’s immune system and helps the body fight infection.

lymphocyte
A type of white blood cell that helps fight infection.

lymphoma
A general term for cancers that develop in the lymphatic system. There are two main types of lymphoma: non-Hodgkin’s lymphoma and Hodgkin’s disease.

malignant
Cancer. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.
**metastasis**
Also know as a secondary cancer. A cancer that has spread from another part of the body.

**oncologist**
A doctor who specialises in the study and treatment of cancer.

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

**PET scan**
A positron emission tomography scan. A technique used to identify cancerous cells in the body.

**plasma**
The clear fluid part of the blood that carries blood cells.

**platelet**
A cell in the blood that helps with blood clotting.

**primary cancer**
The original cancer. Cells from the primary cancer may be carried to other parts of the body, where secondary cancers can form.

**prognosis**
The likely outcome of a person’s disease.

**radiotherapy**
The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

**recurrent cancer**
A cancer that grows from cells of a primary cancer that have resisted treatment.
red blood cells
Also called erythrocytes. One of three types of cells found in the blood. They carry oxygen around the body.

relapse
The return of a disease after a period of improvement or remission.

remission
Period of time when the symptoms of the cancer reduce or disappear. A partial remission is when there has been a significant improvement in the cancer. A complete remission is when there is no evidence of active disease. This does not necessarily mean that the cancer is cured.

side effect
Unintended effects of a drug or treatment.

staging
Tests to find out how far a cancer has spread.

stem cells
Early-stage blood cells from which other cells develop.

tissue
A collection of cells that make up part of the body.

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 or malignant.

white blood cells
Also called leucocytes. One of three types of cells found in the blood. White blood cells help to fight infection. The types of white blood cells include neutrophils, lymphocytes and monocytes.
How you can help

At the Cancer Council NSW we’re dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

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

Make a donation: any donation whether large or small will make a meaningful contribution to our fight to defeat cancer.

Buy your sun protection products from our website or our retail stores: every purchase helps you prevent cancer and contributes financially to our work.

Help us speak out and create a cancer-smart community: the Cancer Council is a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us defeat cancer by living and promoting a cancer-smart lifestyle.

To find out more about how you or your family and friends can help, please call 1300 780 113.
Regional offices

**Central and Southern Sydney Region**
153 Dowling Street
Woolloomooloo NSW 2011
(PO Box 572
Kings Cross NSW 1340)
Ph: (02) 9334 1900
Fax: (02) 9334 1739

**Far North Coast Region**
101-103 Main Street
Alstonville NSW 2477
Ph: (02) 6627 0300
Fax: (02) 6628 8659

**Hunter Region**
22 Lambton Road
Broadmeadow NSW 2292
Ph: (02) 4961 0988
Fax: (02) 4961 0955

**Mid North Coast Region**
121 High Street
Coffs Harbour NSW 2450
Ph: (02) 6651 5732
Fax: (02) 6652 1530

**North West Region**
Shop 2
218 Peel Street
Tamworth NSW 2340
Ph: (02) 6766 1164
Fax: (02) 6766 7053

**Northern Sydney and Central Coast Region**
The Hive, Erina Fair
622-650 Terrigal Drive
Erina NSW 2250
Ph: (02) 4367 4500
Fax: (02) 4367 5895

**South West Region**
1/37 Tompson Street
Wagga Wagga NSW 2650
Ph: (02) 6937 2600
Fax: (02) 6921 3680

**Southern Region**
1 Lowden Square
Wollongong NSW 2500
Ph: (02) 4225 3660
Fax: (02) 4225 1700

**Western Sydney Region**
43 Hunter Street
Parramatta NSW 2150
Ph: (02) 9687 1399
Fax: (02) 9687 1118

**Western Region**
84 Byng Street
Orange NSW 2800
Ph: (02) 6361 1333
Fax: (02) 6361 1863
Cancer Council Helpline 13 11 20
For support and information on cancer and cancer-related issues, call the Cancer Council Helpline. This is a free and confidential service.

For further information and details please visit our website:
www.cancercouncil.com.au