Understanding Non-Hodgkin’s Lymphoma

A guide for people with cancer, their families and friends
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Note to reader
Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor’s or health professional’s advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Cancer Council New South Wales
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 defeat cancer, phone 1300 780 113 or visit Cancer Council’s website at www.cancercouncil.com.au.
Different lymphomas

There are two main types of lymphatic cancers: non-Hodgkin's lymphoma (85% of cases) and Hodgkin's lymphoma. The difference between the lymphomas is how they look under a microscope. A cell called Reed-Sternberg is visible in Hodgkin’s lymphoma, but it isn’t found in non-Hodgkin’s lymphoma.

This booklet is about non-Hodgkin’s lymphoma, but if you need information on Hodgkin’s lymphoma, call the Cancer Council Helpline on 13 11 20.

Introduction

This booklet has been prepared to help you understand more about non-Hodgkin’s lymphoma.

Many people feel understandably shocked and upset when told they have non-Hodgkin’s lymphoma. We hope this booklet will help you understand how the 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 on page 45.
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, 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 may develop into a lump called a tumour.

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. However, if a benign tumour continues to grow at the original site, it can cause a problem by pressing on nearby organs.

A malignant tumour is made up of cancer cells, which grow out of control and are able to spread. When it first develops, a
malignant tumour may not have invaded nearby tissue. This is known as a cancer in-situ (carcinoma in-situ) or localised cancer. As the tumour grows, it may invade surrounding tissue, becoming invasive 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 non-Hodgkin’s lymphoma, which is a type of blood cancer, the cancer cells usually affect and enlarge your lymph nodes at one or more lymph node sites around the body. The cancer cells can spread to any organ, in particular, the spleen, liver, brain, spinal cord and bone marrow. This is called a secondary cancer or metastasis.

A metastasis keeps the name of the original cancer. For example, non-Hodgkin’s lymphoma that has spread to the liver is still called non-Hodgkin’s lymphoma.
Non-hodgkin’s lymphoma is a cancer of the white blood cells that starts in the lymphatic system. The lymphatic system is a key part of the immune system, which protects the body against disease and infection.

The lymphatic system includes a network of thin tubes (lymph vessels) found all over the body, as well as a number of organs, such as the spleen and thymus gland (see next page).
Lymph vessels carry a clear fluid called lymph. This fluid travels to and from the tissues before being emptied into the bloodstream. Lymph contains white blood cells called lymphocytes, which help fight infection.

There are two main types of lymphocyte: B-cells and T-cells. These cells are produced in the bone marrow. While the B-cells mature in the bone marrow, the T-cells travel to the thymus gland and mature there.

Along the lymph vessels is a network of small, bean-shaped structures called lymph nodes or glands. Lymph nodes are found throughout the body, including the neck, underarms, chest, abdomen and groin.

When germs are trapped in the lymph nodes, the nodes become swollen. This is a sign that your body is fighting an 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 cells, abnormal cells and bacteria.
- **thymus gland** – found inside the rib cage, behind the breastbone. It contains lymphocytes and helps filter waste products from the blood.
- **tonsils** – a collection of lymphatic tissue at the back of the throat that traps inhaled or ingested germs.
- **bone marrow** – the soft spongy material inside bones. Bone marrow makes three types of blood cells: oxygen-carrying red blood cells, infection-fighting white blood cells including lymphocytes, and cells called platelets, which help the blood to clot.
Non-Hodgkin’s lymphoma – Q&A

Q: What is non-Hodgkin’s lymphoma?
A: Non-Hodgkin’s lymphoma is a type of lymphoma, which is a general term for cancers that develop in lymphatic tissue. Sometimes non-Hodgkin’s lymphoma is called B-cell lymphoma or T-cell lymphoma, depending on the type of cells affected.

If you have non-Hodgkin’s lymphoma, your lymphocytes become damaged. They grow abnormally and multiply uncontrollably, causing your lymph nodes to enlarge and form painless lumps called tumours. As the abnormal lymphocytes replace the normal ones, your immune system becomes less effective.

Non-Hodgkin’s lymphoma may occur in a single lymph node, a group of lymph nodes or in another organ. Non-Hodgkin’s lymphoma can sometimes appear at the same time in several parts of the body.

Q: What types are there?
A: There are many different types of non-Hodgkin’s lymphoma. They are grouped according to different features that can be seen under a microscope, including the type of cell affected: either B-cells or T-cells. B-cell lymphoma is more common than T-cell lymphoma.

Non-Hodgkin’s lymphoma is also classified as either slow growing (known as low-grade or indolent lymphoma) or fast growing (known as high-grade or aggressive lymphoma).
Q: What are the causes?
A: The causes of non-Hodgkin’s lymphoma are unknown. For most people there is no identifiable reason they have the disease. However, there are some risk factors that may increase a person’s chance of developing it. These include:
• immune system deficiency caused by infections such as human immunodeficiency virus (HIV), human T lymphotrophic virus (HTLV-1), herpes virus 8 or Helicobacter pylori
• taking drugs that affect the immune system (immuno-suppressants) after an organ transplant, or for HIV or an autoimmune disease
• having an autoimmune disease (e.g. rheumatoid arthritis)
• a diet high in animal fats, including red meat and dairy products.

Q: How common is it?
A: Non-Hodgkin’s lymphoma is the seventh most common cancer in NSW, with about 1,300 people being diagnosed each year. Most non-Hodgkin’s lymphoma occurs in adults. The chance of developing it increases as you get older. It also occurs in children, and it is a common cancer in adolescents and young adults.

Q: What are the symptoms?
A: Often the first sign of non-Hodgkin’s lymphoma is a painless swelling of a lymph node, usually in the neck, underarm or groin. Other symptoms may include unexplained fever; sweating, particularly at night; weight loss; tiredness and itchy skin.

Sometimes lymphoma starts in the lymph nodes in deeper parts of the body, such as the abdomen (causing bloating) or the chest (causing coughing, discomfort and difficulty breathing).
Diagnosis

Some symptoms of non-Hodgkin’s lymphoma are common to many illnesses, such as the flu or a virus. Most people with these symptoms will not have lymphoma. However, if your doctor suspects that you do, you will initially have a physical examination to check for signs of lymph node swelling in your throat, tonsils, neck, abdomen, underarms and groin. You will also have a biopsy and you may have a blood test to check your bone marrow, kidney and liver.

Biopsy
A diagnosis is made by removing the enlarged lymph node, or part of it, and examining the cells under a microscope. This is called a biopsy, which can be done in different ways:

**Excision biopsy** – You will have a local or general anaesthetic, depending on how deep the lymph node is. The doctor cuts out (excises) the whole node. You will have some stitches while your wound heals, and you may be in hospital for a few days.

**Needle core biopsy** – A piece of tissue is removed from the lymph node with a needle. Local anaesthetic is used to numb the area. It usually takes 30–60 minutes to perform.

**Fine needle aspiration biopsy** – A very thin needle is inserted into the tumour to remove a small amount of tissue or fluid. It is a quick procedure done without anaesthetic. It is less common as it doesn’t usually provide enough tissue for a full diagnosis, but it helps to determine the need for a core biopsy or excision biopsy.

It takes about a week to find out the test results, and waiting may make you anxious. It can help to talk things over with someone you trust.
Further tests
If the biopsy shows you have non-Hodgkin’s lymphoma, you will then usually have a few of the tests described on pages 11–14. These will show whether cancer has spread to other parts of your body (staging). Staging helps your doctor recommend the best treatment for you. For more information on staging, see page 15.

Blood tests
Blood is taken to see how well your kidney and liver are working. These organs may not work properly if lymphoma is present. Blood samples are also taken regularly to check your blood counts, which is a measure of the different levels of red blood cells, white blood cells and platelets.

• Low levels of red blood cells can cause anaemia, which makes you tired, dizzy, pale and breathless.

• Low levels of white blood cells may mean you not only get more infections, but they are harder to shake off.

• Low platelet levels can cause you to bruise easily, get frequent nosebleeds or have prolonged bleeding from cuts.

Low blood counts may also indicate the non-Hodgkin’s lymphoma has spread to the bone marrow.

Bone marrow biopsy
This procedure determines whether there are any lymphoma cells in the bone marrow.

A needle is used to remove a small piece of bone marrow from the pelvis or breastbone. This biopsy is usually done with a local anaesthetic to the bone and the surrounding skin. A bone marrow biopsy only takes a few minutes, but it may be uncomfortable. Your doctor can give you pain-killers if needed.
CT scan

A CT (computerised tomography) scan is a procedure that uses x-ray beams to take pictures of the inside of your body and show if the lymph nodes are enlarged. 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 need to lie still on a table while the large, round CT scanner slowly rotates around you. This painless test takes 30–60 minutes, and most people can go home as soon as the scan is finished.

If you have a pacemaker or other metallic object in your body, you can’t have an MRI scan due to the effect of the magnet.

If you are allergic to iodine, fish or dyes, you need to tell the person performing a CT scan or MRI scan in advance as you may not be able to have the special dye.

MRI

Magnetic resonance imaging (MRI) uses magnetism and radio waves to build up detailed cross-section pictures of your body. You will need to lie in a narrow metal cylinder. If confined spaces concern you, talk to your health care team before the scan. It may be helpful to take a mild sedative, or you can talk to the person operating the MRI machine through an intercom during the procedure.
**PET scan**

A PET (positron emission tomography) 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 30–90 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, but the preparation and scan will take several hours.

**Gated heart pool scan**

This scan helps assess your heart’s function and pumping ability. It may be done if certain drug treatments are planned for you. A small amount of your blood is taken, mixed with some radioactive material and re-injected into you. As the radioactive material is pumped through the heart, it becomes visible on a computer screen, allowing doctors to see how your heart is working. The radioactive substance is safe. The scan takes about 45 minutes.

**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, showing where the non-Hodgkin's lymphoma has spread. This test is not common.
Lumbar puncture
This is a type of biopsy that allows doctors to examine the fluid around the spine to see whether lymphoma cells have travelled to the spinal cord through the blood. The fluid is obtained from your lower back using a thin needle. A lumbar puncture can be done under x-ray guidance for people with spinal disease or arthritis.

Chest x-ray
This may be done to check for enlarged lymph nodes in the chest or lungs.

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 predict the exact course of your illness.

While some people may be cured of non-Hodgkin’s lymphoma after initial treatment, other people experience multiple episodes of the disease, going in and out of remission (absence of disease symptoms) over several years.

Assessing prognosis
Test results, the type of lymphoma you have, the rate of cancer 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.
Stages of non-Hodgkin’s lymphoma

Different stages describe how far the lymphoma has spread. Each stage is also assigned a letter – ‘A’ means you have no symptoms; ‘B’ means symptoms are present, such as fever, night sweats and unexplained weight loss. Your doctor can explain your stage to you.

Stage I – only one lymph node area or one area or organ outside the lymph nodes are affected.

Stage II – two or more lymph node areas are affected on one side of the diaphragm only.

Stage III – lymph nodes on both sides of the diaphragm are affected.

Stage IV – lymphoma has spread outside the lymph nodes, for example, to the liver, lungs or bone.
Which health professionals will I see?

Your GP will 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, a doctor who specialises in diseases of the blood, lymphatics and bone marrow. This specialist will arrange further tests, make a diagnosis, advise you about treatment options, coordinate and prescribe treatment, and support you throughout your illness.

Other health professionals who specialise in different aspects of your treatment will also care for you. This multidisciplinary team may include:

- **radiation oncologist** – a doctor who prescribes and coordinates the course of radiotherapy
- **nurses** – give the course of treatment and support you through all stages of your illness
- **dietitian** – recommends the best eating plan to follow while you are in treatment and recovering
- **pharmacist** – dispenses and advises you on different medications
- **social worker, physiotherapist, occupational therapist and psychologist** – talk to you about support services and help you to resume normal activities. See *Seeking support* on page 37 for more information.
Not everyone will have the same treatment. When planning your treatment, your doctor will look at a number of factors including your age and general health, whether you have low-grade lymphoma or aggressive lymphoma, and which parts of your body are affected.

**Low-grade lymphoma**

Some lymphoma, called low-grade or indolent lymphoma, grows very slowly and causes few problems as there is little change in the disease. Your doctor may decide that you don’t need treatment initially but will monitor your health with regular checkups and blood tests. This is called watchful waiting. If there is a change or growth in the lymphoma that causes symptoms, and other warning signs appear, your doctor will then recommend treatment, which is usually chemotherapy but can include radiotherapy and biological therapies. See pages 18–22 for information about these treatments.

Some people find the watchful waiting approach hard to accept and would rather have treatment straightaway. However, doctors recommend watchful waiting for low-grade lymphoma because clinical studies have shown that treatment given at an early stage may not affect the outcome of the disease, but it often causes side effects.

Many people with low-grade lymphoma continue their usual activities without disruption for many years. If they need to have treatment, often this stops the active disease and they go into remission for a long time, but later they may need treatment again.
**Aggressive lymphoma**

Aggressive lymphoma grows much faster than low-grade lymphoma and needs treatment as soon as possible. Chemotherapy is the main initial treatment.

There are other options to control the lymphoma, such as radiotherapy, a peripheral blood stem cell transplant or biological therapies. You may have one of these treatments or a combination.

**Chemotherapy**

Chemotherapy is the use of cytotoxic drugs, which kill or slow the growth of cancer cells. Other fast-growing cells are also affected, such as the cells involved in hair growth, cells in the mouth and blood cells in the bone marrow.

The aim of chemotherapy is generally to control the lymphoma so that you go into remission. Sometimes chemotherapy can be used for palliative care (see page 27).

Chemotherapy is usually given in tablet form or intravenously. You may be on a drip or have the drugs through a device called a tube or a line. Different types include:

- **PICC (peripherally inserted central catheter)** – a thin tube put into your arm
- **port-a-cath (port)** – a thin tube put into a vein with an opening (port) on your chest or arm
- **central line** – a thin tube inserted into a vein in the chest or neck.

Occasionally people need a small amount of chemotherapy given via a lumbar puncture (see page 14) to either prevent or treat a lymphoma in the brain or spinal cord. This is called intrathecal chemotherapy. The procedure usually only takes a few minutes.
Usually you will have chemotherapy as an outpatient, but you may need to stay in hospital sometimes. After each course of treatment, your doctor will monitor your progress and do tests to see how the drugs have affected the lymphoma. The treatment may be repeated several times until the lymphoma goes into remission.

**Interactions with other medicines**

It’s important to tell your doctor about any other prescription or over-the-counter medicines, herbal remedies, antioxidants or nutritional supplements you’re taking, as these may affect how chemotherapy works in your body.

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**Side effects**

Many people continue to work and carry out their day-to-day activities while having chemotherapy, but some drugs can cause side effects, such as feeling sick, mouth sores, tiredness, infertility and hair loss.

Most side effects will go away after treatment ends, but it is important to discuss any you are experiencing with your doctor or nurse. They may be able to give you medication or advice to help relieve your symptoms.

For more information about coping with side effects, see Cancer Council’s free booklet *Understanding Chemotherapy*. 
Taking care with infections

People being treated for lymphoma are more prone to infection, particularly when they are having chemotherapy. This is because chemotherapy reduces your blood cell levels, making it harder for your body to fight infections. Colds and flu may linger, and scratches and cuts may get infected easily.

Ask relatives or friends with a cold or the flu to wait until they are well before visiting. Naturally this is not practical for the people you live with, so just use your commonsense and avoid close contact if they are ill.

See your doctor if you are unwell when you are having chemotherapy, as even minor illnesses such as a cold can become a serious health problem.

Contact your doctor or go to the nearest hospital emergency department immediately if you experience:

- a fever over 38° C (keep a thermometer handy to check your temperature)
- 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 motions
- infections at the site of your injections
- prolonged faintness and a rapid heartbeat.
Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply. It affects all tissue within the treatment area, but your treatment will be carefully planned to do as little harm as possible to your healthy cells.

A course of radiotherapy is usually given daily over several weeks. Each session usually lasts for only a few minutes, but it can take some time to set up the equipment. How long you have treatment for will depend on the type of non-Hodgkin’s lymphoma you have and your general health.

Radiotherapy is painless and you should not feel any discomfort during each session. While you are being treated, you will lie alone in a room under a large machine that delivers x-ray beams to the treatment area. You will still be able to talk to the radiation therapist through an intercom.

Side effects
Radiotherapy can cause side effects, but most will go away in time and there are ways to reduce the discomfort they cause.

Tiredness and local skin irritation are the most common side effects of radiotherapy. It may also reduce your blood counts. Other side effects will depend on the part of the body being treated. Radiotherapy to the abdomen may upset the stomach and cause diarrhoea. It may also affect fertility. Radiotherapy to the neck can affect taste and make your mouth sore and dry.

For more information, see the booklet Understanding Radiotherapy, available for free from the Cancer Council Helpline.
**Biological therapy**

Biological therapies (also called biotherapies) include a range of treatments developed from natural substances in the body, usually proteins. They are concentrated and purified for use as drugs. The therapies work in different ways to help the body fight cancer.

**Monoclonal antibodies** – work by targeting diseased cells, attaching to them and then destroying them. Medication is given intravenously and is used alone or with other treatments for certain types of lymphoma. The monoclonal antibodies available in Australia for lymphoma include rituximab and alemtuzumab.

**Immunotherapy** – increases the strength of the immune system so that it is able to attack cancer cells more effectively. One treatment is interferon, which is a hormone-like protein made by white blood cells. It is injected under the skin. The use of vaccines to help the main treatment (adjuvant therapy) for lymphoma is under investigation but is not an established treatment.

**Granulocyte-colony stimulating factor (G-CSF)** – helps white blood cells recover faster following chemotherapy. You may have the treatment under the skin (subcutaneously) or intravenously. G-CSF is also sometimes used in stem cell transplants to help blood stem cells multiply quickly (see page 24).

### Tip

Arrange to go to the hospital with a relative or friend if you can. You may feel unwell and weak following treatment, so it’s helpful if someone can take you home.

**Side effects**

Side effects are specific to the medication used. They are very uncommon with some (e.g. G-CSF or rituximab), but more common with others (e.g. interferon). Talk to your doctor about what may occur.
Radioimmunotherapy
Radioimmunotherapy – or radioactive antibody treatment – is only available in a limited number of treatment centres. It is a type of targeted radiotherapy using monoclonal antibodies to deliver radiation to the cancer cells. It may be used when some types of lymphoma come back after initial treatment. It can cause side effects that are similar to those caused by monoclonal antibodies (e.g. fever, nausea or rashes) or radiotherapy. Your doctor will tell you what to expect if you have this treatment.

Steroid therapy
Steroids are made naturally in the body, but they can also be produced artificially and used as drugs. Corticoid steroids are often given with chemotherapy to help destroy the lymphoma. Steroid therapy is usually given for a few weeks.

Side effects
The type of side effects people experience vary, depending on the dose and how long they have the steroid therapy. Most side effects are temporary and will gradually disappear after you stop taking the medication.

Steroids given for a short time may cause increased appetite, feelings of restlessness, insomnia and weight gain.

If taken for several months, steroids may cause puffy skin (fluid retention or oedema), high blood pressure, high blood glucose levels and diabetes. You are more likely to get infections and, over time, your skin, muscle and bones may weaken.

Your medical team will monitor the treatment, but if you are worried about side effects, talk to your doctor.
Peripheral blood stem cell transplant

A peripheral blood stem cell transplant may be an option if the lymphoma returns. In this procedure, high doses of chemotherapy destroy the lymphoma before the transplant of stem cells restores bone marrow function and your blood counts.

The general transplant process is described here, but your health care team will explain the procedures for your individual transplant because they vary from person to person.

Stem cells are early-stage cells from which blood cells develop. Most stem cells are found in the bone marrow, but small amounts are found in your blood. These are called peripheral blood stem cells.

There are two types of transplants. You may have either type, depending on your circumstances:
- **autologous transplant** – your own stem cells are extracted from your body, stored and re-injected after chemotherapy
- **allogeneic transplant** – stem cells are collected from another person (a donor) and injected into your body after chemotherapy.

If your own stem cells are used, you will usually be given granulocyte-colony stimulating factor (G-CSF) to help the stem cells multiply quickly and be released from the bone marrow into the blood. When enough stem cells have been made, they will be collected from a vein with a needle or small tube.
Treatment

First, a drug helps the 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.

After chemo, the stem cells are thawed and put back.

This is a simple overview of the transplant process. Your case may be different.
After the stem cells are collected, they are separated from the other blood cells by pumping the blood through a cell-separating device called an apheresis machine. The stem cells are processed and frozen using liquid nitrogen (cryopreserved). The other blood cells are returned to your body.

You will then be given high-dose chemotherapy, which kills the cancer cells. It will also destroy your own blood-forming cells in the bone marrow, which can cause side effects (see below).

A day or so after chemotherapy, your stem cells will be thawed and returned to you via a vein.

**Side effects**

High-dose chemotherapy, and the transplant itself, can cause temporary side effects, such as fatigue, nausea, vomiting, diarrhoea, mouth sores or hair loss. Your blood counts will also be low, which increases your risk of picking up infections.

After the transplant, your blood counts will be low for a while and you will probably continue to have side effects caused by chemotherapy, including fatigue. In time, these symptoms will go away as you recover. For more information about coping with side effects, see the free booklet *Understanding Chemotherapy*, available from Cancer Council.

If you’ve had an allogeneic transplant, you’ll be watched carefully for any signs of graft-versus-host disease (GVHD). In GVHD, the donor’s cells in the transplanted tissue (the graft) attack your own
body tissue (the host), which can cause problems in many of your organs. After the transplant, your doctor will give you drugs to reduce the risk of GVHD and to try to treat the problem if it occurs.

**Recovery**
When your blood counts have risen and your general health improves, you can go home, but you will need regular follow-up care as an outpatient to check your progress. The time it takes to recover varies depending on your situation. Your nurse will be able to talk to you about what you might expect while you recuperate.

You can also talk to someone from the Cancer Council Helpline (13 11 20) for support and advice.

**Palliative treatment**
Palliative treatment helps to improve people’s quality of life by alleviating symptoms of cancer without trying to cure the disease. It is particularly important for people with advanced cancer. However, it is not just for people who are about to die and it can be used at different stages of cancer.

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 symptoms. Treatment may include radiotherapy, chemotherapy, blood transfusions and medication.

For more information on palliative treatment or advanced cancer, call the Helpline for free copies of the booklets *Understanding Palliative Care* or *Living with Advanced Cancer*, or view them online at [www.cancercouncil.com.au](http://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 you don’t have time to think things through, but there is usually time 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 by information, others want as much information as they can find. Making sure you understand enough about your illness, the treatment and its side effects will help you make your own decisions.

- If you are offered a choice of treatments, you need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, especially those that affect your lifestyle.

- If you have a partner, you may want to talk about treatment options. You can also talk to friends and family.

- If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.

You have the right to accept or refuse any treatment.

Some people with more advanced cancer 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 options that don't try to cure the cancer but make them feel as well as possible.
Talking with doctors

When your doctor first tells you that you have cancer, it is very stressful and you may not remember much. You may want to see the doctor a few times before deciding on treatment.

If your doctor uses medical terms you don’t understand, it’s okay to ask for a simpler explanation. You can also check a word’s meaning in the glossary (see page 45).

Before you see the doctor, it may help to write down your questions. Taking notes 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.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor’s recommendations and reassure you that you have explored all of your options. Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.

Your doctor can refer you to another specialist and send them your initial results. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You may decide you would prefer to be treated by the doctor who provided the second opinion.
**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 to see if they are better than current treatments.

If you are unsure about joining the 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 – such as questions to ask your doctor and how to find a trial that may be suitable for you – call the Helpline on 13 11 20 for a free copy of *Understanding Clinical Trials*.
Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and improve well-being. Addressing changes in your emotions and relationships early on is also very important.

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

The Cancer Council Helpline can send you information about nutrition, including the free booklet *Food and Cancer*.

**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.

If you aren’t used to exercise or haven’t exercised for a while, make small changes to your daily activities. You could walk to the shops, take the stairs, or do some gardening. To do more vigorous exercise or weight-bearing exercise, ask your doctor what is best for you.
Complementary therapies

Complementary therapies may help you 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, meditation, 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. Self-help CDs or DVDs can also guide you through some different techniques.

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.

Call the Helpline for a copy of Cancer Council’s CD Relaxation for People with Cancer. and for the publications Understanding Complementary Therapies and Massage and Cancer: an introduction to the benefits of touch.

Alternative therapies are commonly defined as those used instead of conventional treatments. These therapies may be harmful if people with cancer delay or stop using conventional treatments in favour of them. Examples include high-dose vitamin supplements, coffee enemas and magnet therapy.
Strengthening your relationships
The strong emotions you experience as a result of cancer may affect your relationships. Your experiences may cause you to develop a new outlook on your values, priorities and life in general. Sharing those thoughts and feelings with your family, friends and work colleagues may strengthen your relationships.

If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after treatment.

While you are giving yourself time to adjust to living with cancer, 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 in their own way to changes. If someone’s behaviour upsets you, it will probably help to discuss how you both feel about the situation.

Sexuality, intimacy and cancer
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 and addressing them will help you adjust to these changes.

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

Call the Helpline on 13 11 20 for more information, including a free copy of the booklet Sexuality, Intimacy and Cancer.
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 common whether your body has changed physically or not.

Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing only on the parts of you that have changed.

For practical suggestions about weight changes and other physical changes, call the Helpline.

Look Good...Feel Better Program

This free program teaches techniques to help restore appearance and self-esteem during treatment. Call 1800 650 960 or visit www.lgfb.org.au.
Life after treatment

You may be surprised to find out that life after cancer treatment can present its own challenges. You will need to take some time to adjust to physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than secure. You might worry about every ache and pain and wonder if the cancer is coming back.

Some people say that after cancer they have changed priorities and see life with a new clarity. For example, you may decide to travel, spend more time with family, or do volunteer work.

Although you might feel pressure to return to normal life, it’s important to remember that you may not want your life to return to how it was before cancer.

You might find it helpful to:
- take time to adjust to physical and emotional changes
- re-establish a new daily routine at your own pace
- maintain a healthy diet and lifestyle
- schedule regular checkups with your doctor
- share your concerns with family and friends and tell them how to support you
- call the Helpline on 13 11 20 to connect with other people who have had cancer, or to request a free copy of the booklet Living Well After Cancer.

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, talk to your doctor. You may be clinically depressed, and counselling or medication may help you.
After treatment: follow-up

After your treatment, you will need regular checkups to monitor the size of your lymph nodes and confirm that the cancer hasn’t come back. Blood tests, x-rays or other scans may be done.

Checkups will become less frequent if you have no further problems.

Between follow-up appointments, let your doctor know immediately of any health problems.

What if the lymphoma returns?

For many people, treatment either cures the lymphoma or controls the disease for several years. This is known as remission, which is when the symptoms and signs of cancer reduce or disappear, and tests become normal or near normal. You will still need regular checkups during this time.

Sometimes people have a relapse, which means the lymphoma has returned after a period of improvement. If this happens, you may be given more treatment to help control the lymphoma again.
When you are first diagnosed with cancer, and throughout the different stages of your treatment and recovery, it is normal to experience a range of emotions, such as fear, sadness, anxiety, anger and frustration. If sadness or anxiety is ongoing or severe, talk to your doctor.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support or you might prefer to talk to:

- members of your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 39
- the Cancer Council Helpline.

If you need assistance, such as help around the house, it may be hard to tell people what would be useful. Some people prefer to ask a family member or friend to coordinate offers of help.

You may find that while some people you know are supportive, others may not even know what to say to you. Cancer Council’s booklet *Emotions and Cancer* may help if this happens to you.

If you have children, the prospect of telling them that you have cancer can be frightening and unsettling. The booklet *When a Parent Has Cancer: how to talk to your kids* can help you prepare for this conversation.
Practical and financial help
A serious illness often causes practical and financial difficulties. This can add to the stress and anxiety you may already be feeling about having cancer and going through treatment.

Many services are available to help so you don’t have to face these difficulties alone.

- Financial assistance, through benefits and pensions, can help pay for prescription medicines and travel to medical appointments.
- Home nursing care is available through community nursing services or local palliative care services.
- Meals on Wheels, home care services, aids and appliances can make life easier.

To find out more, talk to the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline. Cancer Council’s booklet Understanding Your Rights may also be useful.

Understanding Cancer program
If you want to learn more about cancer and ways to cope with it, you may find the Cancer Council’s Understanding Cancer program helpful. The program offers practical information and discussions about many issues people experience after diagnosis.

Topics covered include what cancer is, cancer symptoms and side effects, treatment, palliative care, diet, exercise and complementary therapies.

Understanding Cancer programs are held frequently at hospitals and community centres throughout NSW. Call the Helpline for more information.
Talk to someone who’s been there

Getting in touch with other people who have been through a similar experience can be beneficial. There are many ways to contact 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.

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 and find out how you can connect with others.

Support services available for patients, carers and family members

- **Face-to-face support groups**, which are often held in community centres or hospitals
- **Online discussion forums** where people can connect with each other any time – see www.cancerconnections.com.au
- **Telephone support groups** for certain situations or types of cancer, which trained counsellors facilitate
- **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.
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. 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 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.

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

Call the Cancer Council Helpline to find out more about different services or to request a free copy of the booklet Caring for Someone with Cancer.
The Cancer Council Helpline is a telephone information service provided by 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 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.
Useful websites

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

**Australian**
Cancer Council NSW ..............................www.cancercouncil.com.au
Cancer Council Australia  .........................www.cancer.org.au
Cancer Institute NSW ..............................www.cancerinstitute.org.au
Leukaemia Foundation ..............................www.leukaemia.com
Lymphoma Support &
Research Association Inc .........................www.lymphoma.org.au

**International**
American Cancer Society ........................www.cancer.org
Macmillan Cancer Support  ......................www.cancerbackup.org.uk
Leukemia & Lymphoma Society of America ..................................www.leukemia.org
Following a cancer diagnosis, many people look for information about new types of treatment, the latest research findings and stories about how other people have coped.

The Cancer Council Library has more than 3,000 resources in the collection, including books, CDs, DVDs, videos and a large range of medical journals.

You can visit the library at 153 Dowling Street, Woolloomooloo (Monday to Friday, 9am to 5pm), 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 free Cancer Council publications relevant:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Emotions and Cancer*
- *Sexuality, Intimacy and Cancer*
- *Food and Cancer*
- *Overcoming Cancer Pain*
- *Caring for Someone with Cancer.*

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.

- What type of non-Hodgkin’s lymphoma do I have?
- What is the stage of the lymphoma and what does that mean?
- What tests do I need?
- What treatment plan do you recommend and why?
- What is my prognosis?
- How long will treatment last?
- How much will treatment cost?
- Will I need to stay in hospital for treatment?
- What are the risks and side effects of each treatment? What side effects should I report?
- Will the treatment affect my sex life and fertility?
- How frequently will I have to have checkups?
- What happens if the lymphoma comes back after treatment?
- Are there any clinical trials of new treatments?
- Are there any complementary therapies that might help me?
You may come across new terms when reading this booklet or talking to health professionals. You can also check the meaning of other words relating to health on Cancer Council’s website, www.cancercouncil.com.au.

**abdomen**
The part of the body between the chest and the hips that contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

**adjuvant therapy**
A treatment given with or shortly after another treatment to enhance its effectiveness.

**advanced cancer**
Cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

**aggressive lymphoma**
A fast-growing type of non-Hodgkin’s lymphoma.

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

**anaemia**
Deficiency in the number or quality of red blood cells in the body. Anaemia decreases the amount of oxygen in the body and may cause tiredness and fatigue, breathlessness, paleness and a poor resistance to infection.

**anaesthetic**
A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a temporary loss of consciousness.

**analgesic**
A drug or natural remedy used to relieve pain.

**antibody**
Part of the body’s immune system. Antibodies are proteins made by the blood in response to an invader (antigen) in the body. They help protect against viruses, bacteria and other foreign substances.

**autologous transplantation**
A transplant where tissue is
taken from a person’s body and reimplanted into their body.

**axillary lymph nodes**
Lymph nodes in and around the armpit.

**B-cell**
A type of white blood cell that is formed and matures in the bone marrow.

**benign**
Not cancerous or malignant. Benign lumps are not able to spread to other parts of the body.

**biological therapies**
A range of treatments that are derived from natural substances found in the body, such as proteins. Also called biotherapies.

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

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

**bone marrow**
The soft spongy material inside bones. Bone marrow produces red blood cells, white blood cells and platelets.

**bone marrow biopsy**
The removal of a small amount of bone marrow with a needle for examination under a microscope.

**cells**
The basic organisational unit of all living things. A human is made of millions of cells, which are adapted for different functions.

**central nervous system**
The brain and the spinal cord.

**chemotherapy**
The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

**clinical trial**
A research study that tests better ways of improving health in people.

**complementary therapies**
Supportive treatments that are used
in conjunction with conventional treatment. They may improve general health, well-being and quality of life, and help people cope with side effects of cancer.

**contraindication**
A medical condition or symptoms that would cause a person to have a bad reaction to a treatment.

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

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

**diagnosis**
The identification and naming of a person’s disease.

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

**granulocyte-colony stimulating factor (G-CSF)**
A protein that helps increase the number and function of certain white blood cells called neutrophils, which help fight infection in the bone marrow.

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

**Hodgkin’s lymphoma**
A type of lymphoma. Also called Hodgkin’s disease.

**hormone**
Chemical messengers in the body that transfer information between cells. They affect many functions such as growth, reproduction and blood sugar levels.

**immune system**
A network of cells and organs that defends the body from foreign invaders like bacteria and viruses.
immunotherapy
The prevention or treatment of disease using substances that alter the immune system’s response. This is a type of biological therapy.

indolent or low-grade lymphoma
A slow-growing cancer that starts in the cells of the lymphatic system.

intrathecal chemotherapy
Chemotherapy given into the spinal fluid via a lumbar puncture.

intravenous
Inserted into a vein.

lumbar puncture
Inserting a small needle between two vertebras to obtain spinal fluid.

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

lymph nodes
Small, bean-shaped structures found along the lymphatic vessels that form part of the lymphatic system. Also called lymph glands.

lymphatic system
A network of tissues, capillaries, ducts and lymph nodes that makes immune cells, removes excess fluid from tissues, and processes fats.

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

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

malignant
Cancer. Malignant cells can spread (metastasise) and can eventually cause death if they can’t be treated.

monoclonal antibodies
A group of medications made from different types of proteins that target specific diseased cells, attach to them and destroy them.

MRI scan
A magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed
cross-sectional pictures 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 specialised imaging test that uses a radioactive glucose solution to identify cancer cells in the body.

**platelets**
One of three types of cells found in the blood. These help the blood to clot and stop bleeding.

**prognosis**
Likely outcome of someone’s illness.

**radiation oncologist**
A doctor who specialises in treating cancer using different forms of radiotherapy.

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

**recurrent cancer**
Cancer that comes back after an initial remission.

**red blood cells**
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.

**remission**
When the symptoms and signs of 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 disease, but this does not necessarily mean that the cancer is cured.

**spleen**
An organ in the lymphatic system
found under the ribs on the left side of the abdomen. The spleen produces lymphocytes, filters blood, stores blood cells, and destroys old blood cells.

**staging**
Performing tests to determine how far cancer has spread.

**stem cells**
Early-stage cells from which mature cells 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 before being replaced by healthy stem cells to restore the function of the bone marrow, blood and immune system. Stem cells are obtained from either the bone marrow or the peripheral blood of the patient or a donor.

**steroid therapy**
Drugs that reduce swelling, pain and other symptoms of inflammation.

**subcutaneous**
Injection under the skin.

**T-cell**
A type of white blood cell that develops in the thymus.

**thymus**
An organ found inside the rib cage, behind the chest. It contains many lymphocytes and helps filter blood.

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

**tumour**
A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

**watchful waiting**
When a person does not receive treatment, but has their health monitored regularly. Sometimes called active surveillance.

**white blood cells**
One of three types of cells found in the blood. They help fight infection. Types of white blood cells include neutrophils, lymphocytes and monocytes.
At 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 sun protection products from our website or retail stores:** Every purchase you make helps you prevent cancer and contributes financially to our work.

**Help us speak out and create a cancer-smart community:** 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.
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Call the Cancer Council Helpline for support and information on cancer and cancer-related issues. This is a free and confidential service. Our website also has many resources. Please visit www.cancercouncil.com.au.