



Cancer
Council

Understanding Non-Hodgkin Lymphoma

A guide for people with cancer,
their families and friends

Cancer
information

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Understanding Non-Hodgkin Lymphoma

A guide for people with cancer, their families and friends

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Note to reader

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

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

Cancer Council NSW

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



Cancer Council NSW

153 Dowling Street, Woolloomooloo NSW 2011

Telephone 02 9334 1900 **Facsimile** 02 8302 3500

Email feedback@nswcc.org.au **Website** cancercouncil.com.au

ABN 51 116 463 846

Introduction

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

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

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by non-Hodgkin lymphoma. It is based on clinical practice guidelines for non-Hodgkin lymphoma.¹

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



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What is blood cancer?

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

Sometimes cells don't grow, divide and die in the usual way. This may cause different kinds of cancer. Most cancers, such as breast or bowel cancer, are solid cancers. In these, the abnormal cells form a lump called a tumour.

Other cancers that affect the blood, bone marrow and lymphatic system are known as blood cancers. There are three main groups of blood cancers: leukaemia, lymphoma and myeloma.

The blood is made up of different types of blood cells. Blood cells are made in the bone marrow – a spongy material in the middle of our bones. The main types of blood cells are red blood cells, white blood cells and platelets. Each of these cell types has a different function in the body (see page 15).

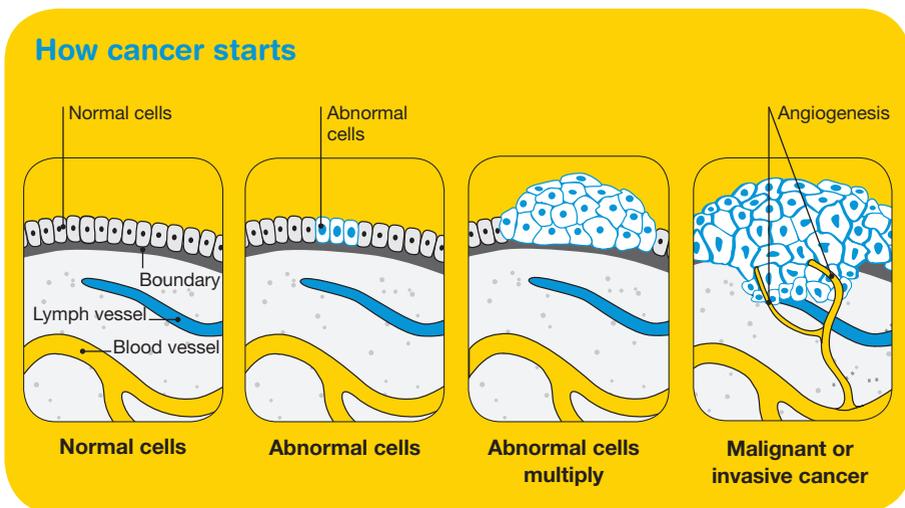
Blood cancers develop when blood cells aren't made properly. In most blood cancers, an abnormal type of blood cell grows out of control and upsets normal cell production.

This can reduce the bone marrow's ability to produce normal levels of other blood cells, which affects the way that the rest of the body works. Meanwhile, the abnormal cells spill out into the bloodstream or the lymphatic system. Without treatment, many of the body's key functions will be increasingly affected.

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

If these abnormal cells continue to build up, they can spread to any part of the lymphatic system. As the damaged lymphocytes multiply and replace normal cells, the body’s immune system becomes less able to fight infections.

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





The lymphatic system

Non-Hodgkin lymphoma is a cancer of the lymphatic system. The lymphatic system is part of the immune system, which protects the body against disease and infection. It consists of:

Lymph vessels – These thin tubes form a large network throughout the body. Lymph vessels carry lymph fluid around the body.

Lymph fluid – This clear fluid travels from the tissues in the body, through the lymph vessels, before being emptied into the bloodstream. It carries nutrients, antibodies and immune cells.

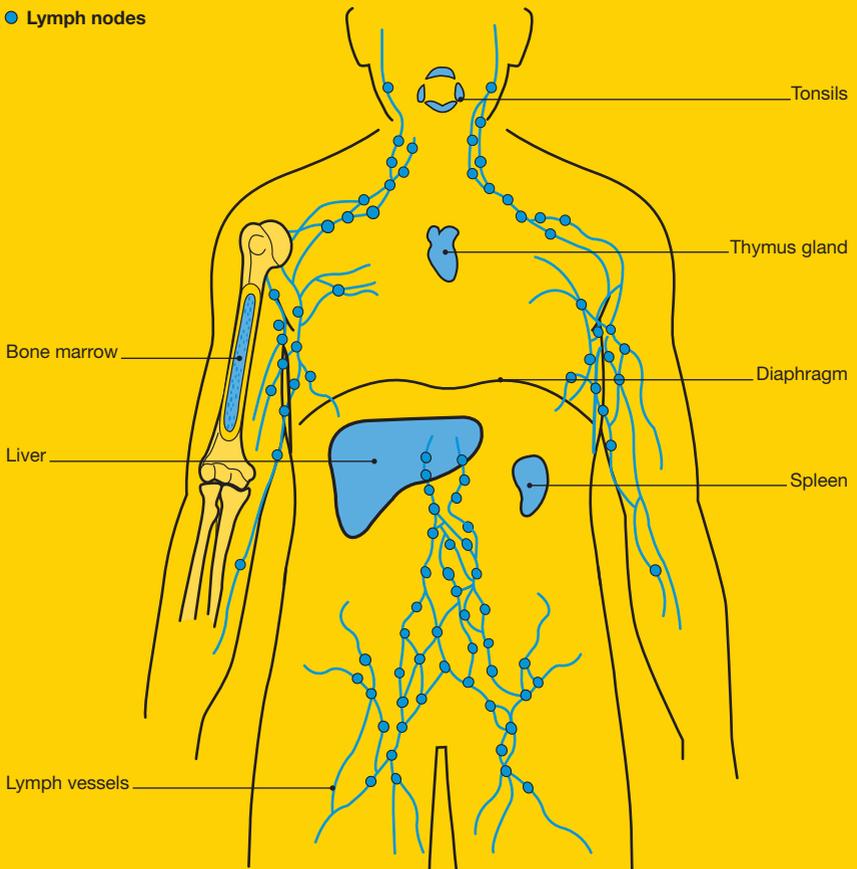
Lymph nodes (glands) – These small, bean-shaped structures are found along the lymph vessels. Lymph nodes are located throughout the body, including the neck, underarms, chest, abdomen and groin. Lymphocytes in the lymph nodes clean the lymph fluid as it passes through the body, helping to remove and destroy bacteria, viruses and other harmful substances. When germs become trapped in the lymph nodes, the lymph nodes swell, which is a sign that lymphocytes have multiplied to fight off the germs. For example, the glands in your neck may swell when you have a sore throat.

Lymph tissue – This is found throughout the body, e.g. in the lymph nodes, spleen, bone marrow, thymus and tonsils.

Lymphocytes – Lymph fluid, lymph nodes and lymph tissue all contain white blood cells called lymphocytes, which help protect the body against disease and infection. The three main types of lymphocytes – B-cells, T-cells and NK-cells – are produced in the bone marrow. Non-Hodgkin lymphoma starts in these blood cells.

Anatomy of the lymphatic system

● Lymph nodes



The lymphatic organs include:

Bone marrow – This is the soft, spongy material inside bones. Bone marrow produces three types of blood cells: red blood cells; white blood cells (including some types of lymphocytes); and platelets. In non-Hodgkin lymphoma, abnormal cells multiply and crowd the bone marrow, reducing its ability to make normal blood cells.

Thymus gland – This is found inside the rib cage, behind the breastbone. The thymus gland helps produce lymphocytes.

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

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

Different types of lymphoma

There are two main types of lymphoma: non-Hodgkin and Hodgkin. Non-Hodgkin lymphoma is more common. The two types look different when the diseased cells are examined under a microscope. A type of lymphocyte called a Reed-Sternberg cell is usually found in Hodgkin lymphoma, but not in non-Hodgkin lymphoma. For a free booklet about Hodgkin lymphoma, call Cancer Council **13 11 20** or visit cancercouncil.com.au.



Key questions

Q: What is non-Hodgkin lymphoma?

A: Non-Hodgkin lymphoma is a blood cancer that affects the lymphatic system. It begins in the white blood cells called lymphocytes (see page 6). It is sometimes called non-Hodgkin's disease.

Most commonly, non-Hodgkin lymphoma starts in a lymph node at one or more places in the body. It can spread through the lymphatic system from one group of lymph nodes to another. It can also spread to other lymph tissue, particularly in the bone marrow, spleen and liver.

Sometimes non-Hodgkin lymphoma starts in or spreads to tissues in other parts of the body, such as the stomach, bone, skin, brain and spinal cord (central nervous system). This is known as extranodal disease.

Q: What types are there?

A: There are many different types of non-Hodgkin lymphoma. It is classified according to whether the cancer started in B-cell, T-cell or NK-cell lymphocytes.

The table on the next page describes some of the more commonly diagnosed types of non-Hodgkin lymphoma. NK-cell lymphomas are very rare.

Non-Hodgkin lymphoma can also be classified by how fast it is growing – see page 28 for more information.

Common types of non-Hodgkin lymphoma

B-cell lymphomas (around 85% of cases)

diffuse large B-cell	a fast-growing cancer that often starts in lymph nodes; the most common type of non-Hodgkin lymphoma in Australia; an intermediate-grade lymphoma
follicular	cancer cells grow slowly in lymph nodes in circular groups called follicles; may be low or intermediate-grade
small lymphocytic	a slow-growing cancer that is similar to chronic lymphocytic leukaemia; a low-grade lymphoma
mantle cell	develops in the outer edge (mantle zone) of B-cells in the lymph nodes; although a low-grade lymphoma, it often acts like a high-grade lymphoma and grows quickly

T-cell lymphomas (around 15% of cases)

precursor T-lymphoblastic	starts in immature (precursor) T-cells in the lymph nodes and the spleen; a high-grade lymphoma
peripheral T-cell	often occurs as widespread enlarged, painless lymph nodes; an intermediate or high-grade lymphoma
cutaneous (skin) T-cell	primarily affects the skin and starts as red, scaly patches or raised bumps that can be itchy; a low-grade lymphoma

Q: What are the risk factors?

A: In most cases of non-Hodgkin lymphoma, the cause is unknown. However, there are some factors that may increase the risk of a person developing non-Hodgkin lymphoma:

Weakened immune system – The immune system is weakened in people with HIV and people taking medicines called immunosuppressants. These include drugs to treat HIV and drugs that are given to people after an organ transplant. People with autoimmune diseases, such as rheumatoid arthritis and coeliac disease, also have a weakened immune system.

Infections – Some infections can slightly increase the risk of non-Hodgkin lymphoma. These include *Helicobacter pylori*, HTLV-1 (human T-lymphotropic virus 1), hepatitis C, Epstein-Barr virus and human herpesvirus 8.

Family history – Having a parent, brother or sister who has had non-Hodgkin lymphoma slightly increases a person's risk of developing it. However, this family link is rare and most people with non-Hodgkin lymphoma do not have a family history.

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



Q: How common is it?

A: Each year in NSW, about 1700 people are diagnosed with non-Hodgkin lymphoma.² It is more common in men than women. Most cases occur in adults aged 60 and older. However, non-Hodgkin lymphoma can also occur in young adults and children.

Q: What are the symptoms?

A: Non-Hodgkin lymphoma can cause different symptoms depending on where it is found in the body. Symptoms may include:

- painless swelling of a lymph node (e.g. in the neck, underarm or groin)
- unexplained and regular fevers
- excessive sweating, particularly at night
- loss of appetite
- unintentional weight loss
- persistent tiredness (fatigue)
- itchy skin (rarely).

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

Symptoms of non-Hodgkin lymphoma are common to many conditions, such as the flu or a virus. If you are concerned, make an appointment to see your general practitioner (GP).



Diagnosis

If your GP suspects that you have non-Hodgkin lymphoma, they will feel the lymph nodes in your neck, underarms and groin to see if they are swollen or enlarged. They will also examine your throat, tonsils, neck, chest and abdomen. Your GP may organise further tests or refer you to a specialist.

Biopsy

Removing some cells and tissue from an enlarged lymph node is the only way to confirm a diagnosis of non-Hodgkin lymphoma. This procedure is called a biopsy and it is done in two main ways.

Excision biopsy

- You will be given a local or general anaesthetic depending on the location of the lymph node.
- The doctor will cut through the skin to remove the whole lymph node.
- The wound will usually be closed with stitches. These will be removed about a week later.
- You may have day surgery or you may be in hospital for a few days.
- This is the preferred type of biopsy for non-Hodgkin lymphoma because it helps ensure an accurate diagnosis and staging of any lymphoma found.

Core needle biopsy

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

After a biopsy, the tissue sample is examined for cancer cells by a specialist doctor called a pathologist. If cancer cells are found, the pathologist can tell which type of non-Hodgkin lymphoma it is. The results will usually be ready in 7–10 days. This waiting period can be an anxious time and it may help to talk to a supportive friend, relative or health professional about how you are feeling.

Further tests

Sometimes further tests are needed to find out whether the cancer has spread. This is called staging (see pages 20–21). The following pages describe tests that are commonly used to help stage non-Hodgkin lymphoma. You will probably not need to have all of these tests – most people will have blood tests (see below) and some imaging tests (see pages 16–18). Some tests may be repeated during or after treatment to check your health and how well the treatment is working.

Blood tests

Your doctor will take a sample of your blood to see how well your kidneys and liver are working, and to check your general health. Low blood counts before treatment may indicate that the cancer has spread to the bone marrow. You will also have regular blood tests to check the effects of treatment on your total number of red blood cells, white blood cells and platelets (see table opposite).

Bone marrow biopsy

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

- **Bone marrow aspiration** – the doctor inserts a needle into the bone at the back of your hip to remove a small sample of fluid (aspirate) from the bone marrow.
- **Bone marrow trephine** – the doctor uses a needle to take a matchstick-wide sample of both bone and bone marrow tissue.

The procedure takes about 30 minutes. It is usually done as an outpatient procedure in hospital. You will lie still while a local anaesthetic is injected into your pelvis (hip) to numb the area. You may also be offered light sedation to help you feel relaxed or a general anaesthetic. You may feel some pressure or discomfort during the biopsy, but this usually lasts no more than a day. You will need to lie flat in bed for another 30 minutes after the biopsy. Ask a member of your health care team about pain-relieving medicine if you feel uncomfortable after the procedure.

Blood cell type	Function	Symptoms if levels are low
red blood cells	carry oxygen around the body	can cause anaemia, which may make you look pale and feel tired, breathless and dizzy
white blood cells	fight infections	may make you more likely to get infections and make it more difficult to get rid of infections
platelets	help your blood to clot	can cause you to bruise easily, have frequent nosebleeds, or have prolonged bleeding from cuts

Imaging tests

You will usually have at least one of the tests described below:

Chest x-ray – Before an excision biopsy, you may have an x-ray of the chest to see if the lymphoma has spread to the lymph nodes in your chest or lungs.

CT scan – A CT (computerised tomography) scan uses x-ray beams to create a detailed three-dimensional picture of the inside of the body. Your chest, abdomen and pelvis will be scanned to check whether the cancer has spread.

Before the scan, you may be asked to drink a liquid or have an injection of a special dye known as a contrast. This helps ensure that anything unusual can be seen more clearly. The dye may make you feel hot all over and leave a strange taste in your mouth for a few minutes.

The CT scanner is large and round like a doughnut. You will lie on a table that moves in and out of the scanner. The scan is painless, but can be noisy, and takes 30–60 minutes. Most people can go home as soon as the scan is over.



The dye used in a CT scan can cause allergies in some people. If you have had an allergic reaction to iodine or dyes during previous scans, let the person performing the scan know in advance. You should also tell the doctor if you're diabetic, have kidney disease or are pregnant.

PET scan – A PET (positron emission tomography) scan is a specialised imaging test that is usually done in combination with a non-contrast CT scan.

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

You will be asked to sit quietly for 30–60 minutes while the glucose moves around your body, then you will have the scan. While it may take a few hours to prepare for a PET scan, the scan itself takes only about 30 minutes. Clinic staff will tell you how to prepare for the scan, particularly if you are diabetic.

Ultrasound – An ultrasound uses soundwaves to create a picture of the internal organs. This test is most commonly used to help find swollen lymph nodes or other lumps in the body.

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

MRI scan – MRI (magnetic resonance imaging) scans are not commonly used for people with non-Hodgkin lymphoma, but may be useful in some special circumstances. The MRI scan

uses magnetism and radio waves to create detailed pictures of a particular area inside the body. You will lie on a treatment table that slides into a metal cylinder. The test is painless, but some people find lying in the cylinder noisy and confined. The MRI scan takes 30–60 minutes, and you will be able to go home when it is finished. Let your doctor know if you have a pacemaker or another type of metal object in your body, as you may not be able to have an MRI scan.

Lumbar puncture (spinal tap)

A lumbar puncture allows the doctor to examine the fluid that protects the brain and spinal cord (the central nervous system). This procedure helps the doctor determine whether there are lymphoma cells within the central nervous system. This is uncommon, so most people with non-Hodgkin lymphoma will not need to have a lumbar puncture.

If you do have a lumbar puncture, you will be placed in a curled or sitting position and given a local anaesthetic. A thin needle will be inserted to remove some fluid from the space between the bones in your lower back. You may feel some discomfort. Tell your doctor if you feel any pain, as they may be able to give you some more anaesthetic.

After the procedure, you may have to lie on your back for a short time to help prevent a headache starting. If you do get a headache, check with your doctor whether you can take pain-relieving medicine. A lumbar puncture can also cause nausea, but this will usually ease within a few hours.



Karen's story

I'd been having check-ups with my GP every six months for a few years due to some ongoing health issues. One year, I let too much time pass between appointments, even though I'd been feeling unwell – eating made me feel nauseous and I couldn't stand to have anything tight around my stomach.

When I did see my GP, I told him about how I'd been feeling and he gave me a physical examination. He booked me in for an ultrasound and a CT scan, which showed an abnormality. I was referred to a specialist and had a liver biopsy and another CT scan. The results suggested that I had lymphoma, and a haematologist sent me for another biopsy under general anaesthetic. After that, the diagnosis of non-Hodgkin lymphoma was confirmed.

Over the next few weeks, I had more tests and was

told the cancer had spread to my liver, spleen and thyroid. My doctor prescribed chemotherapy once a fortnight for four months.

I received the standard chemotherapy drugs for the first few months of treatment, and I took part in a clinical trial for the last four sessions. The doctor was very pleased with how well the new drugs worked.

During the week I had treatment, I would feel okay as the nurses would give me medicine. The next week, I would get side effects like diarrhoea, vomiting and constipation. I took ginger to help with the nausea, and I tried to live my normal life whenever I felt well enough.

I had such good support from work, my family and friends, and the hospital staff were brilliant. I still have regular check-ups and I'm back to living my usual active life.

Staging

The test results help your doctors determine the stage of the cancer and the appropriate treatment for you. The diagram opposite describes the different stages of non-Hodgkin lymphoma.

As well as a number, each stage is assigned a letter according to whether you are experiencing specific symptoms:

- “A” means you feel well, with none of the B symptoms of non-Hodgkin lymphoma.
- “B” means you have some or all of these symptoms – unexplained fevers, unexplained weight loss or drenching night sweats.

Prognosis

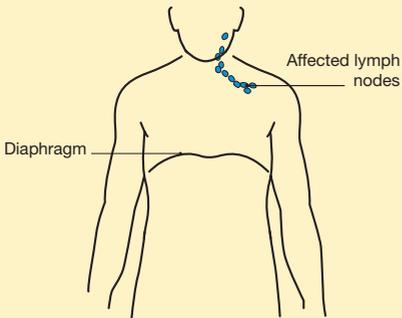
Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your haematologist (or medical oncologist if they are your main treating specialist). However it is not possible for anyone to predict the exact course of your disease. Instead, your doctor can give you an idea about common issues that affect people with your type of non-Hodgkin lymphoma.

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

Stages of non-Hodgkin lymphoma

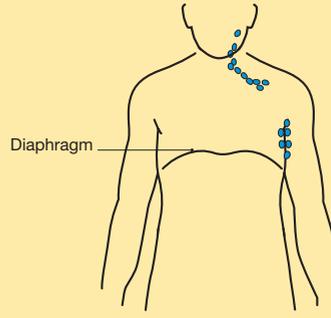
Staging describes how far the cancer has spread throughout the body. Your doctor can explain your stage to you in more detail.

Stage I



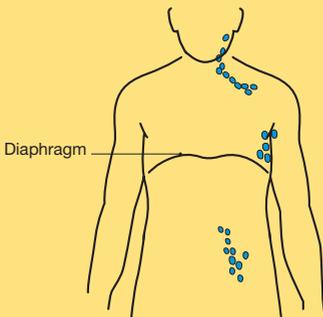
One lymph node area is affected. This is either above or below the diaphragm.

Stage II



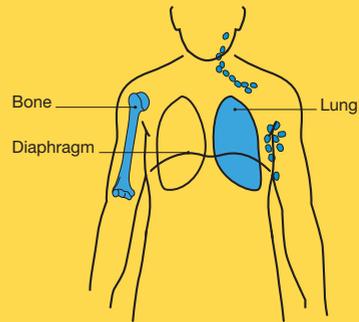
Two or more lymph node areas are affected on the same side of the diaphragm.

Stage III



Lymph node areas both above and below the diaphragm are affected.

Stage IV



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

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

People may experience multiple episodes (recurrences) of the disease, meaning they go in and out of remission over several years. See page 51 for more information about treatment for recurrence.

Which health professionals will I see?

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

You will probably be cared for by a range of health professionals who specialise in different aspects of your treatment. A list of people who may be in this multidisciplinary team (MDT) is on the opposite page.



If you live in a regional or rural area, you may need to travel for treatment. The NSW Government provides financial help to people who need to travel long distances to access specialist medical treatment not available in their local area. For more information, visit enable.health.nsw.gov.au/services/iptaas or phone **1800 478 227**.

Health professional	Role
haematologist*	specialises in diagnosing and treating diseases of the blood, the lymphatic system and bone marrow; coordinates all aspects of patient care, including chemotherapy, targeted therapy, stem cell transplants, and referral for radiation therapy if required
medical oncologist*	treats cancer with drug therapies such as chemotherapy; in some cases, may be the main treating specialist instead of a haematologist
radiation oncologist*	prescribes and coordinates the course of radiation therapy
radiation therapist	plans and delivers radiation therapy
cancer care coordinator, clinical nurse consultant	supports patients and families during treatment; liaises with other members of the health care team
nurse	administers drugs, including chemotherapy; provides care, information and support throughout all stages of treatment
dietitian	recommends an eating plan to follow during treatment and recovery
pharmacist	dispenses medicines and provides advice about drugs, dosage and side effects
counsellor, social worker, psychologist	provide counselling and emotional support; advise you on support services
physiotherapist, occupational therapist	help with physical or practical issues

** Specialist doctor*



Key points

- If your GP suspects that you have non-Hodgkin lymphoma, they will carry out a physical examination to check whether your lymph nodes are enlarged or swollen.
- A biopsy is the only way to confirm a diagnosis of non-Hodgkin lymphoma. All or part of the lymph node will be removed and the cells will be examined under a microscope.
- If the biopsy shows that you have non-Hodgkin lymphoma, you will have further tests to find out whether the cancer has spread. This process is called staging and helps your doctors work out the most appropriate treatment for you.
- Blood tests can check how well your liver and kidneys are functioning. A blood count involves checking the number of red blood cells, white blood cells and platelets.
- You will have regular blood tests to track the progress of the disease.
- You may need a bone marrow biopsy. This is when a needle is inserted into the pelvic bone to extract small samples of fluid and bone for examination.
- Many people will also have a CT or PET-CT scan. Other tests may include ultrasound, x-ray, MRI scan and lumbar puncture.
- Your doctor may talk to you about your prognosis. This means the expected outcome of the disease.
- People treated for non-Hodgkin lymphoma can go into complete remission or may experience multiple episodes during their lifetime.
- You will be treated by a haematologist and other health professionals working together in a multidisciplinary team.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values.

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

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember everything you're told. Taking notes or recording the discussion may help. Many people like to have someone go with them to take part in the discussion, take notes or simply listen. If you are confused or need clarification, you can ask questions (see suggestions page 56). If you have several questions, you may want to talk to a nurse or see if you can book a longer appointment.

Listen to a discussion about "Making Treatment Decisions" at cancercouncil.com.au/podcasts.



A second opinion

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

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by the first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

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



Treatment

When planning your treatment, your doctor will consider the type of non-Hodgkin lymphoma you have, the stage, your age and general health, and your preferences.

The aim of treatment is to control the cancer so you go into remission (see page 22). Remission may last for a long period of time. Sometimes non-Hodgkin lymphoma becomes active again and further treatment is required.

Preparing for treatment

Heart function – Radiation therapy to the chest and some types of chemotherapy may affect the way your heart works (see page 40).

Your doctor may recommend you have some tests before, during and/or after treatment to check your heart function.

Fertility – Some treatments for non-Hodgkin lymphoma can cause infertility, meaning you will no longer be able to have children. If having children is important to you, ask your doctor before treatment starts about whether there are options for preserving your fertility.

You may be able to store sperm, eggs, ovarian tissue or embryos. Call **13 11 20** and ask for our *Fertility and Cancer* booklet, or download a copy from cancercouncil.com.au.

Dental check-up – If possible, see a dentist before having chemotherapy, a stem cell transplant or radiation therapy to the head and neck area. If mouth and teeth problems are left untreated, they can lead to infections after cancer treatment. For more information, read our *Mouth Health and Cancer Treatment* fact sheet.

Grading of non-Hodgkin lymphoma

One of the most important factors your doctors will take into account when deciding on treatment is how fast the lymphoma is growing.

Low-grade (slow growing) – Doctors may call this indolent lymphoma. It may cause few symptoms in the beginning because there is little change in the cancer over time.

You may not need treatment straightaway. If there is a change or growth in the cancer that causes symptoms or other warning signs, your doctor will recommend treatment, usually with chemotherapy (see pages 29–34). You may also have targeted therapy (pages 36–37) and radiation therapy (pages 38–39).

Intermediate-grade and high-grade (fast growing) – Doctors may also call these aggressive lymphomas. They grow much faster than low-grade non-Hodgkin lymphoma and need to be treated as soon as possible to have the best chance of destroying the cancer and causing remission.

Chemotherapy is the main treatment for aggressive non-Hodgkin lymphoma. You may also have another type of treatment, such as radiation therapy (see pages 38–39) or a stem cell transplant (see pages 41–45).

You will usually be offered chemotherapy in combination with rituximab (see page 36) if you have a B-cell lymphoma.

👤👤 I did the Look Good Feel Better program before treatment. It helped me prepare mentally for losing my hair during chemotherapy. 👤👤 *Ann*

Watchful waiting

If you are diagnosed with low-grade non-Hodgkin lymphoma (see opposite), you may not have treatment straightaway. Instead you may have regular check-ups to monitor the cancer. This approach is called watchful waiting (or watch and wait).

Having treatment earlier than necessary can cause unpleasant side effects. It can also make your body resistant to treatment, so if you need it later, it may not work as well. Many people with untreated low-grade non-Hodgkin lymphoma continue their usual daily activities for many years.

Some people find watchful waiting difficult to accept and prefer to have treatment immediately. If waiting for treatment makes you feel anxious, speak with your medical team. They may be able to put you in touch with someone who has had a similar experience.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells or slow their growth. For non-Hodgkin lymphoma, chemotherapy is often combined with other treatments. It is also sometimes given as palliative treatment.

Generally, chemotherapy is given into a vein in your arm through a drip (intravenously). It may also be given through a narrow tube called a port, catheter or venous access device. The type of tube depends on how often you need chemotherapy, how long it takes to give each dose, and how long the device needs to stay in place.

Types of intravenous devices

PICC (peripherally inserted central catheter)	A thin tube that can stay in place for a long period of time. A PICC is inserted into a vein in the arm.
port-a-cath (port)	A small device with a dome-shaped opening (port) that is surgically inserted beneath the skin in the chest or arm. A tube called a catheter connects the port to a vein so fluids can be passed into the body.
central line (central venous catheter or CVC)	A thin tube with several openings that is inserted into a vein in the neck or chest.
cannula	A small, hollow plastic tube that is inserted into the hand or arm.

Some chemotherapy drugs for non-Hodgkin lymphoma are given as tablets. Occasionally, chemotherapy is given via a lumbar puncture (see page 18). This is called intrathecal chemotherapy, and it is done to prevent or treat non-Hodgkin lymphoma in the brain or spinal cord.

Treatment is usually given as a combination of drugs spread over 4–6 months. The drug combination and treatment schedule will depend on the type of non-Hodgkin lymphoma. While each person's schedule varies, generally chemotherapy is given over a few days, followed by a rest period to allow the blood counts to return

to normal before the next round of chemotherapy. As chemotherapy can affect the production of blood cells, you will have regular blood tests to check your blood count, and your liver and kidney function.

Many people have chemotherapy as an outpatient, although at times you may need a short stay in hospital. Throughout the treatment, you will be closely monitored by your doctor and you will have tests to see how well the chemotherapy drugs are working. Chemotherapy treatment may be repeated several times until tests show that the cancer is in remission.

You may also be given injections of a substance known as granulocyte-colony stimulating factor (G-CSF) to help increase your white cell count and protect you from infection.

Side effects of chemotherapy

Chemotherapy drugs can harm healthy, fast-growing cells, such as the cells in your hair, mouth and blood. This causes side effects. Some people don't experience any side effects, others have several.

During chemotherapy, you may be able to continue to work and carry out your daily activities, but you may need extra rest when you feel tired. Discuss any side effects you experience with your doctor or nurses. Most side effects are temporary. Your treatment team can help you prevent or manage any side effects.

Some of the common side effects experienced by people who have chemotherapy for non-Hodgkin lymphoma are described on pages 32–33.

Common side effects of chemotherapy

Everyone reacts to chemotherapy differently. For more information about chemotherapy and its side effects, call Cancer Council **13 11 20**, or visit cancercouncil.com.au to download the *Understanding Chemotherapy* booklet.



Increased risk of infections

Chemotherapy reduces your white blood cell level, making it harder for your body to fight infections. Colds and flu may be easier to catch and harder to shake off, and scratches or cuts may get infected more easily. You may also be more likely to catch a more serious infection without any obvious cause and need to be admitted to hospital. See page 34 for ways to reduce your risk of infection.

Nausea and vomiting

You will generally be given anti-nausea medicines with each chemotherapy session to help prevent you feeling sick (nausea) or vomiting. These are usually very effective. If you still have nausea or vomiting after using the prescribed medicine, let your nurse or doctor know so that another medicine can be tried. For other ways to ensure your body is well nourished throughout treatment, see Cancer Council's *Nutrition and Cancer* booklet.



Constipation

Some chemotherapy drugs and anti-nausea medicines can cause constipation. Ways to help prevent constipation include drinking 6–8 glasses of water a day, eating a high-fibre diet and getting some daily exercise. Your treatment team may also suggest or prescribe a suitable laxative or stool softener.





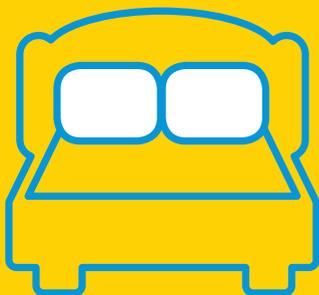
Heavy bleeding from minor cuts, or bruising easily

A drop in the number of platelets in your blood can cause heavy bleeding from small cuts or make you more prone to bruises. You may be given a transfusion of platelets to minimise your risk of bleeding.



Hair thinning/hair loss

Your hair will grow back after treatment, but it may look or feel different. If you have private health insurance, check with your provider whether you are entitled to a rebate on a wig for hair loss due to chemotherapy. Visit cancercouncil.com.au to download a fact sheet on *Understanding Hair Loss*.



Fatigue

Severe tiredness and lack of energy (fatigue) may make you feel drowsy, exhausted or confused. These feelings can last for several weeks or months after having chemotherapy. Check with your doctor whether your fatigue is related to a low red blood cell count (anaemia). This can be treated by blood transfusions. Exercise has been shown to help reduce fatigue (see page 48).



Listen to Cancer Council NSW's podcast episodes on "Appetite Loss and Nausea" and "Managing Cancer Fatigue" at cancercouncil.com.au/podcasts.

Taking care with infections

Reduce your risk

To prevent the spread of infection:

- check with your doctor about having the flu vaccine
- ask people close to you to consider having a flu shot
- ask family or friends with a cold, flu or other contagious infection (e.g. measles, chickenpox or a cold sore) to wait until they are well before visiting
- as far as practical, avoid close contact with people you live with if they are unwell
- try to avoid crowded places, such as shopping centres or public transport in peak hour
- wash your hands with soap and water before preparing food and eating, and after using the toilet
- ensure you prepare and store food properly to avoid foodborne illnesses and food poisoning
- eat freshly cooked foods; avoid raw fish, seafood, meat, eggs and soft cheeses; wash fruits and vegetables well before eating.

When to seek medical help

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

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

Steroid therapy

Steroids are hormonal substances made naturally in the body. They can also be produced artificially and used as a drug. The steroids that are prescribed to treat non-Hodgkin lymphoma are called corticosteroids.

Steroid therapy is often given with chemotherapy drugs to increase their effectiveness, help destroy the lymphoma, and treat any nausea or vomiting. Corticosteroids are usually taken in tablet form, but they can also be given intravenously.

Side effects of steroid therapy

Steroid therapy can cause various side effects, which depend on the dose prescribed and the duration of treatment. Most side effects will be temporary and will gradually disappear after you stop taking the medicine.

If you take corticosteroids for a short period of time, side effects may include an increased appetite, feelings of restlessness, inability to sleep (insomnia), weight gain and mood changes.

If you are prescribed steroid therapy for several months, you may experience fluid retention (a build-up of fluid in the body), high blood pressure and high blood glucose levels. You could also develop diabetes. There is an increased risk of developing stomach ulcers, so your doctor should prescribe an anti-ulcerant drug while you are on steroid therapy. You may also be more likely to get infections (see table opposite) and, over time, your skin, muscles and bones may weaken.

Speak to your doctor if you feel there are significant changes in your mood while you are taking corticosteroids. The doctor may adjust your dose or recommend you see a psychologist or psychiatrist for ways to help you cope with mood changes. Your medical team can help you manage or reduce side effects, especially if these effects are causing you discomfort.

Targeted therapy

Targeted therapy drugs target specific molecules on the surface of cancer cells. The type of targeted therapy most frequently used to treat some types of non-Hodgkin lymphomas is a group of drugs called monoclonal antibodies.

These medicines are manufactured versions of immune system proteins called antibodies, which are part of the body's natural defence against infection. These synthetic antibodies target and attach to cancer cells. This makes it easier for the body's immune system to find and destroy these cells.

Monoclonal antibodies are generally given through a drip into a vein or as an injection under the skin, usually in combination with chemotherapy. They are commonly given in repeating cycles. Talk to your doctor about your specific treatment schedule.

Rituximab is a monoclonal antibody commonly used for many types of B-cell lymphomas. It does not work for T-cell or NK-cell lymphomas. Some B-cell lymphomas that do respond to rituximab may become resistant.

Side effects of monoclonal antibodies

Your doctor will discuss any potential side effects with you before you start treatment. Some people may have a reaction (e.g. nausea, skin rashes and itching) during or several hours after the infusion of these drugs. You will probably be given medicine to help prevent such a reaction and you will be monitored during treatment. Other side effects can include headache, fatigue, anaemia, flu-like symptoms and an increased risk of abnormal bleeding.

In some people, rituximab can reactivate some viral infections, such as hepatitis B. It can also increase your risk of getting another infection (see page 34). It is important to discuss any side effects with your doctor immediately. If left untreated, some symptoms can become life-threatening.

Small molecule inhibitors

Small molecule inhibitors are another type of targeted therapy. These drugs can get inside cancer cells and block certain enzymes that tell the cancer cells to grow.

Two small molecule inhibitors, ibrutinib and idelalisib, have become available to treat some types of low-grade lymphoma that have not responded to treatment or have come back. Talk with your doctor about whether these treatments (or another drug available on a clinical trial) are suitable for your situation.

These drugs have the potential to cause a variety of side effects – your doctor will discuss these with you before treatment.

Radiation therapy

Radiation therapy (also known as radiotherapy) uses x-rays to damage or kill cancer cells so they cannot multiply. Treatment is carefully planned to target the parts of the body affected by lymphoma with carefully directed beams of radiation that minimise the dose to surrounding healthy body tissue.

Radiation therapy for non-Hodgkin lymphoma can be used on its own or after chemotherapy:

- to treat some early-stage, low-grade non-Hodgkin lymphomas
- in certain circumstances in combination with chemotherapy (known as chemoradiation)
- to treat a specific tumour that is growing rapidly, bleeding or causing pain, which sometimes happens after chemotherapy has stopped working
- as part of an allogeneic transplant (see page 41).

Before starting treatment, you will have a planning appointment that will include a CT scan. The radiation therapy team will use the images from the scan to plan your treatments. The radiation therapist may make some small permanent tattoos or temporary marks on your skin so that the same area is targeted during each treatment session.

The radiation oncologist will review your imaging scans throughout treatment to determine the appropriate amount of radiation and the areas to be targeted, and to ensure that the radiation therapy will be as accurate as possible. The overall course of treatment will depend on the type of non-Hodgkin lymphoma and your general health.

You will usually have treatment as an outpatient once a day, Monday to Friday, for about 3–4 weeks. Each session lasts for only 15 minutes (including setting up, checking and treating the area), but it can take longer to wait for your appointment. The radiation oncologist will discuss your treatment schedule with you.

During treatment, you will lie alone in a room under a large machine called a linear accelerator that delivers x-ray beams to the area being treated. You will be able to talk to the radiation therapist through an intercom. Radiation therapy is painless, and you should not feel any discomfort during the sessions.

Side effects of radiation therapy

Radiation therapy may cause side effects, such as tiredness, loss of appetite, skin irritation and hair loss at the treatment area. These side effects can build up towards the end of the course of treatment, but most will be temporary.

Other side effects depend on the part of the body being treated. For example, radiation therapy to the abdomen may cause an upset stomach, nausea, diarrhoea and infertility; while radiation therapy to the neck can make your mouth and throat sore and dry, cause difficulty swallowing, and affect your sense of taste. Most of these side effects will improve within one month of finishing treatment, with the exception of infertility.

For more details about the side effects you may experience, talk to your doctor, call Cancer Council 13 11 20 for a free copy of *Understanding Radiation Therapy*, or visit cancercouncil.com.au.

Late effects of treatment

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

Second cancers – Occasionally, many years after successful lymphoma treatment, patients may develop a new unrelated cancer. This may be either a new form of lymphoma or leukaemia, or a type of solid cancer. Sometimes this happens because of being diagnosed at a young age with lymphoma, being treated with certain chemotherapy drugs, or having a genetic predisposition. In some cases, radiation therapy can also increase the risk of developing a second cancer near the area treated.

Heart problems – Some forms of drug treatments may damage the heart muscle so it doesn't work as well. If this is a concern for you, your doctor will monitor your heart function throughout treatment to limit your risk of developing this condition. They will adjust your chemotherapy if early changes are seen. Radiation therapy to the chest may also lead to heart disease.

Thyroid problems – Radiation therapy to the neck area may cause an underactive thyroid gland, and you may need daily thyroid pills.



It is important that you talk to your doctor about any symptoms that appear, even many years after treatment. Modern treatment plans are, however, designed to reduce these late effects.

Stem cell transplant

Stem cells are unspecialised cells from which blood cells develop. Most stem cells are found in the bone marrow, but a small number are also found in the blood – these are called peripheral blood stem cells.

If non-Hodgkin lymphoma returns (recurs) or does not respond to initial treatment, you may need high doses of chemotherapy to help destroy the cancer cells. This can also damage the stem cells, and you may need a stem cell transplant to help restore the bone marrow and rebuild your immune system.

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

Autologous transplant – when your stem cells are removed from your blood and later transplanted (reinfused) back into your body. This is the most common type of transplant recommended to treat non-Hodgkin lymphoma.

Allogeneic transplant – when the stem cells are collected from another person (a donor). This type of transplant is less commonly used as a treatment for non-Hodgkin lymphoma.

A stem cell transplant is a major procedure and not all people are suitable candidates. Your doctors will talk to you about what is involved. You will also have a range of tests to assess your ability to handle the transplant process and tolerate the high-dose chemotherapy.

Autologous stem cell transplant steps

This is a general outline of a transplant using your own stem cells. The process varies from person to person. Talk to your health care team about what to expect.

1 Mobilising stem cells

- The first stage is to stimulate the production of stem cells.
- You will usually be given a dose of chemotherapy (see page 29) before having injections of a special growth factor drug called granulocyte-colony stimulating factor (G-CSF).
- G-CSF can cause bone pain. Ask your health care team about pain-relieving medicine.
- You will be given G-CSF for 5–10 days to help the stem cells in the bone marrow multiply as quickly as possible. When the bone marrow is full of stem cells, excess stem cells will spill into the blood. This process, called mobilisation, takes several days.
- You will have regular blood tests to check whether there are enough stem cells in your blood.

2 Collecting and storing stem cells

- When enough stem cells are in your blood, they will be collected in a cell-separating machine. This process is called apheresis.
- The machine separates the blood – the white blood cell layer containing the stem cells is collected and the remaining blood is returned to your body.
- Generally, a needle will be inserted into each arm. One needle will draw the blood out of your body and into the machine for separation. The other needle will return the remaining blood to your body.
- In some people, blood will be taken from a vein in the neck or chest using a catheter.
- Blood is removed and returned to your body continuously for 3–4 hours. Only a small amount of blood will be out of your body at any time.
- The stem cells are processed and frozen using liquid nitrogen (cryopreserved).
- You will then have a rest period at home for about a month before the next stage.

3

Receiving high-dose chemotherapy

- In the week before the transplant, you'll have high-dose chemotherapy to kill any remaining cancer cells.
- Before and after the chemotherapy is given, you will have fluids through a drip to prevent dehydration and kidney damage.
- You may experience side effects from the chemotherapy, such as nausea, diarrhoea and mouth sores.
- The chemotherapy will also destroy the stem cells in your bone marrow, which can cause side effects (see page 44).
- Because your stem cells have been destroyed, your blood count will be low and you will be more at risk of infections (see page 34).

4

Transplanting stem cells and engraftment

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

More detailed information about stem cell transplants is available at leukaemia.org.au.



Sometimes the stem cells will be collected directly from the bone marrow by suction (aspiration) under general anaesthetic. This is called a bone marrow harvest. This is not a common procedure.

Recovery and side effects after a transplant

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

After the chemotherapy and transplant, you will have a low blood count. This will lower your immunity and make you more likely to get infections. You may be given antibiotics to treat infections, and will need to avoid contact with people with a cold, flu or other contagious infection. See *Taking care with infections* on page 34 for some ways to reduce your risk.

Your blood counts and general health will be monitored regularly by your doctor after the transplant. You may need occasional blood and platelet transfusions for a short period after the transplant.

Many transplant side effects are similar to the side effects of chemotherapy (see pages 32–33). Occasionally they can be more severe. Side effects may include: nausea and vomiting; diarrhoea; hair loss; infection; mouth ulcers; fatigue; and poor appetite.

Your doctor and nurses will help you manage any side effects you experience after a stem cell transplant.

You will need regular follow-up care to check your progress and how well the treatment has worked. It is not uncommon to become unwell after a transplant and have to go back into hospital. The time it takes to fully recover from a transplant varies. Talk to your health care team about what to expect while you recover. You can also call Cancer Council 13 11 20 for support.

Palliative treatment

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

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

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, social, practical and spiritual needs. The team also provides support to families and carers. Your care may be led by a specialist palliative care team or by your GP and a community nurse.

As well as slowing the spread of cancer, palliative treatment can relieve any pain and help manage other symptoms. There is no

single program of palliative treatment – the treatment you are offered will be tailored to your individual needs.

Palliative treatment for non-Hodgkin lymphoma may include radiation therapy, chemotherapy, targeted therapy or other medicines to help manage symptoms such as pain, bleeding and ulceration, or to help shrink a tumour obstructing the lung or abdomen. It may take time to find the most effective treatment – let your palliative care team know if a treatment is not working as they may be able to offer an alternative.

For more information read our *Palliative Care* or *Living with Advanced Cancer* booklets – for free copies, call Cancer Council 13 11 20 or visit cancerCouncil.com.au.

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



Key points

- Your doctor will recommend treatment based on the type of non-Hodgkin lymphoma you have, the stage, your age and general health, and your preferences.
- Low-grade non-Hodgkin lymphoma grows very slowly and causes few symptoms. Some people with this type of cancer do not have treatment right away, but have regular check-ups instead. This is called watchful waiting.
- Intermediate and high-grade non-Hodgkin lymphomas grow more quickly and need immediate treatment.
- The main treatment for aggressive non-Hodgkin lymphoma is chemotherapy. The aim of treatment is to stop the active cancer and cause remission.
- Chemotherapy can be given in tablet form or intravenously. Treatment will be given as short sessions over several months, with rest periods of a few weeks between each session.
- Radiation therapy uses x-rays to kill cancer cells or injure them so they cannot multiply. It is given Monday to Friday for about 3–4 weeks.
- Targeted therapy and steroid therapy are often combined with other treatments, such as chemotherapy.
- A stem cell transplant may be an option if the cancer returns or does not respond to initial treatment. You will be in hospital for 1–4 weeks and recovery will take time.
- Palliative treatment and supportive care may be given to relieve the symptoms of advanced non-Hodgkin lymphoma.



Looking after yourself

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

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Cancer Council's *Nutrition and Cancer* booklet has more information about eating well during and after cancer treatment.

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

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

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

Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality, intimacy and fertility

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

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

Call 13 11 20 for free copies of *Sexuality, Intimacy and Cancer*, *Emotions and Cancer* and *Fertility and Cancer*. Visit cancercouncil.com.au to download the booklets or to listen to Cancer Council NSW's podcast episode on "Sex and Cancer".

Life after treatment

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

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

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

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning, or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medicine – even for a short

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

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to beyondblue.org.au or call their support service on **1300 22 4636**.

Follow-up appointments

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back and to manage any side effects of treatment.

Your follow-up schedule will depend on the type of non-Hodgkin lymphoma you were diagnosed with and the treatment you had. Your doctor may want to see you three to four times a year for the first couple of years. Check-ups will become less frequent if you have no further problems. Your doctor will talk to you about the best follow-up schedule for your situation.

During these check-ups, you will have a physical examination, blood tests and, possibly, scans. Your doctor will also discuss any new symptoms or late effects of treatment (see page 40). Between follow-up appointments, let your doctor know immediately of any health problems or new symptoms.

What if non-Hodgkin lymphoma returns?

For some people, non-Hodgkin lymphoma does come back after treatment. This is known as a recurrence or relapse. Non-Hodgkin lymphoma that has recurred can be treated, with the aim of causing remission or relieving symptoms.

Treatment for a recurrence usually includes chemotherapy, targeted therapy and, sometimes, radiation therapy. If the cancer is more advanced or aggressive, your doctor may recommend a stem cell transplant combined with high-dose chemotherapy (see pages 41–45).



Seeking support

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

Practical and financial help

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

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

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

Talk to someone who's been there

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

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

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

Types of support

There are many ways to connect with others for mutual support and to share information. Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

Options include:

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

The Thing About Cancer podcast

For more information about all things cancer, listen to Cancer Council NSW's audio podcast series, *The Thing About Cancer*. The episodes cover a wide range of topics, from the first experience of getting a diagnosis, through the process of weighing up treatment options and managing side effects, to explaining cancer to kids and dealing with some of the longer term issues of recovery. To listen, go to cancercouncil.com.au/podcasts.





Caring for someone with cancer

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

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

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

Carers NSW is a state-wide organisation specifically for carers. Visit carersnsw.org.au or phone 1800 242 636 for more information and resources, including about respite services and short-term counselling. You can also call Cancer Council 13 11 20 to find out more about carers' services or to request a copy of the *Caring for Someone with Cancer* booklet.



Cancer Council NSW's podcast *The Thing About Cancer* has an episode focusing on the carer's role. Listen to "Cancer Affects the Carer Too" at cancercouncil.com.au/podcasts.



Useful websites

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

Australian

Cancer Council NSW	cancercouncil.com.au
Cancer Australia	canceraustralia.gov.au
Australasian Leukaemia & Lymphoma Group	allg.org.au
Australian Cancer Trials.....	australiancancertrials.gov.au
beyondblue.....	beyondblue.org.au
Carer Gateway.....	carergateway.gov.au
Carers NSW.....	carersnsw.org.au
Department of Health	health.gov.au
Healthdirect Australia	healthdirect.gov.au
Leukaemia Foundation.....	leukaemia.org.au
Lymphoma Australia.....	lymphoma.org.au
Radiation Oncology: Targeting Cancer.....	targetingcancer.com.au
<i>The Thing About Cancer</i> podcasts ..	cancercouncil.com.au/podcasts

International

American Cancer Society.....	cancer.org
Cancer Research UK.....	cancerresearchuk.org
Leukemia & Lymphoma Society (US)	lls.org
Lymphoma Research Foundation (US).....	lymphoma.org
Macmillan Cancer Support (UK).....	macmillan.org.uk
National Cancer Institute (US)	cancer.gov



Question checklist

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

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



Glossary

abdomen

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

advanced cancer

Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer). Some forms of advanced lymphoma may respond well to appropriate therapy.

allogeneic transplant

A type of transplant where the stem cells are taken from one person and given to another.

anaemia

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

anaesthetic

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

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.

apheresis

The process of separating different types of blood cells using a machine. Apheresis is one of the key steps in a stem cell transplant.

autologous transplant

A type of transplant where stem cells are taken from a person's body and then given back following high-dose chemotherapy.

B-cell

A lymphocyte that forms and matures in the bone marrow.

biopsy

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

blood cancer

A broad term for cancers that affect the blood, bone marrow and lymphatic system.

blood count

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

bone marrow

The soft, spongy material inside bones, which produces red blood cells, white blood cells and platelets.

bone marrow aspiration

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

bone marrow trephine

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

cells

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

chemotherapy

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

CT scan

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

cutaneous T-cell lymphoma

A type of non-Hodgkin lymphoma that affects the skin.

diaphragm

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

diffuse large B-cell lymphoma

A fast-growing type of non-Hodgkin lymphoma that starts in lymph nodes in the neck, armpit or groin.

Epstein-Barr virus

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

excision biopsy

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

extranodal lymphoma

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

fertility

The ability to conceive a child.

follicular lymphoma

A slow-growing type of non-Hodgkin lymphoma that affects B-cells. The cancer cells grow in circular groups called follicles.

granulocyte-colony stimulating factor (G-CSF)

A growth factor used to stimulate the development of stem cells before collection for a transplant or to increase the number of white blood cells if they are low. It is given either as an injection or through a drip into the bloodstream (intravenously).

growth factor

A protein that stimulates the development and growth of cells.

haematologist

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

HIV (human immunodeficiency virus)

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

Hodgkin lymphoma

One type of cancer of the lymphatic system. Also called Hodgkin's disease.

immune system

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

intrathecal chemotherapy

Chemotherapy drugs that are delivered via a lumbar puncture.

intravenous (IV)

Injected into a vein.

liver

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

lumbar puncture

A test in which a needle is inserted into the base of the spine to collect fluid for testing or to inject drugs for treatment. Also called a spinal tap.

lymph

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

lymphatic system

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

lymph glands

See lymph nodes.

lymph nodes

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

lymphocyte

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

lymphoma

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

lymph vessels

Thin tubes that carry the body's tissue fluid (lymph) all over the body.

mantle cell lymphoma

A type of non-Hodgkin lymphoma that develops in the outer edge (mantle zone) of B-cells.

monoclonal antibodies

A group of targeted therapy drugs that lock onto a specific protein on the surface of cancer cells and interfere with the cells' growth or survival.

MRI scan

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

NK-cell

The least common type of lymphocyte. **non-Hodgkin lymphoma** One of the types of cancer that start in the cells of the lymphatic system. Can be low-grade (slow-growing) or high-grade (fast-growing). Also called non-Hodgkin's disease.

palliative treatment

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

pathologist

A specialist doctor who interprets the results of tests (such as blood tests and biopsies).

peripheral T-cell lymphoma

A type of non-Hodgkin lymphoma of T-lymphocytes that often starts as

painless lymph nodes in the neck, armpit or groin.

PET-CT scan

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

platelets

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

precursor T-lymphoblastic lymphoma

A type of non-Hodgkin lymphoma that starts in immature (precursor) T-cells in lymph nodes and the spleen.

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form (see extranodal lymphoma).

prognosis

The expected outcome of a person's disease.

radiation oncologist

A doctor who specialises in treating cancer with radiation therapy.

radiation therapy

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

recurrence

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

red blood cells

One of three types of cells found

in the blood. Red blood cells carry oxygen around the body.

remission

When the signs and symptoms of the cancer reduce or disappear. A partial remission is when there has been a significant reduction in symptoms but some cancer is still present. A complete remission is when there is no evidence of active cancer. This may not mean that the cancer is cured.

small lymphocytic lymphoma

A type of slow-growing lymphoma affecting the B-cells. It is similar to chronic lymphocytic leukaemia.

small molecule inhibitors

A group of targeted therapy drugs that can get inside cancer cells and block proteins that tell the cells to grow.

stem cells

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

stem cell transplant

A treatment in which diseased blood cells are destroyed by high-dose chemotherapy or radiation therapy, then replaced by healthy stem cells. The healthy stem cells may come from the bone marrow (bone marrow transplant), from the bloodstream (peripheral blood stem cell transplant) or from umbilical cord blood (cord blood transplant).

steroids

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

steroid therapy

Treatment with drugs to reduce inflammation, pain and swelling.

targeted therapy

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread. The two main types of targeted therapy at present are monoclonal antibodies and small molecule inhibitors.

T-cell

A lymphocyte that is produced in the bone marrow and matures in the thymus gland.

thymus gland

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

tissue

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

transfusion

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

watchful waiting

When a person does not need immediate treatment, but instead has their health monitored regularly, with the option of future treatment if necessary.

white blood cells

One of three types of cells found in the blood. White blood cells help fight infection. Types include neutrophils, lymphocytes and monocytes.

Can't find a word here?

For more cancer-related words, visit Cancer Council NSW's website at cancercouncil.com.au/words.

References

1. Australian Cancer Network Diagnosis and Management of Lymphoma Guidelines Working Party, *Clinical Practice Guidelines for the Diagnosis and Management of Lymphoma*, Cancer Council Australia and Australian Cancer Network, Sydney, 2005.
2. Cancer Institute NSW, "Non-Hodgkins lymphoma (NHL) statistics". Available from: <https://www.cancerinstitute.org.au/understanding-cancer/cancer-in-nsw/non-hodgkins-lymphoma>. [Accessed 20 November 2017.]



How you can help

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

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

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

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

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

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

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



Cancer Council

13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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

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



**Cancer
Council**
13 11 20

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

For further information and details, visit our website, cancercouncil.com.au.

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