Cancer Council

Understanding Lung Cancer

A guide for people with cancer, their families and friends

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First edition published 1997
Revised May 2003, April 2005, June 2007, July 2010

ISBN 978 1 921619 16 8

Understanding Lung Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy of the booklet is up to date. To obtain a more recent copy, phone the Cancer Council Helpline on 13 11 20.

Acknowledgements
This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils.

We thank the reviewers of this booklet: Dr Nick Pavlakis, Medical Oncologist, Department of Medical Oncology, Royal North Shore Hospital; Jocelyn McLean RN, MN (Res), Case Manager for Thoracic Surgery, Sydney South Western Area Health Service, Eastern Zone; Eileen Ryan, Consumer.

This booklet was developed in collaboration with The Australian Lung Foundation. We thank the health professionals who reviewed this booklet on behalf of the Foundation and Glenda Colburn, Program Development Manager, National Lung Cancer Program.

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

Illustrations on pages 4–5 were adapted from Cancer Council Victoria.

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Printer: SOS Media Group (Alexandria NSW)

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, visit Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.

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Introduction

This booklet has been prepared to help you understand more about lung cancer.

Many people feel shocked and upset when told they have lung cancer. We hope this booklet will help you understand how lung cancer 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 questions and help you think about questions to ask your doctors or other health carers.

You may like to pass this booklet to 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.

How this booklet was developed

The information in this booklet was developed with help from medical experts and people who have been diagnosed with lung cancer. The booklet is based on clinical practice guidelines for lung cancer.

Contents

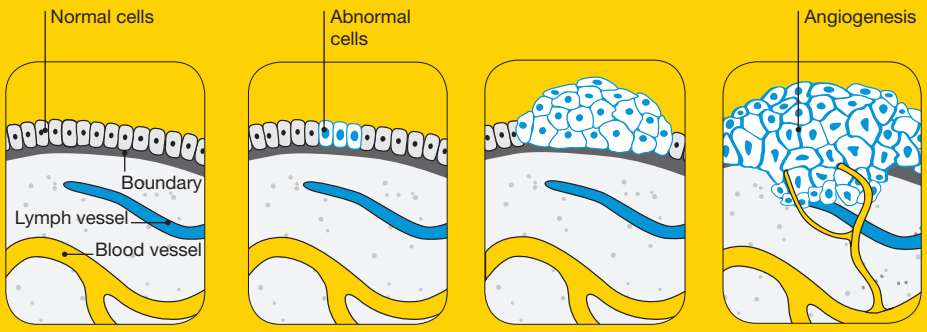
What is cancer?

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, to replace worn-out cells and 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 to other parts of the body. A malignant tumour is made up of cancer cells, which grow out of control and are able to spread. The place where a cancer begins

The beginnings of cancer



Normal cells

Abnormal cells

Abnormal cells multiply
(Cancer in-situ)

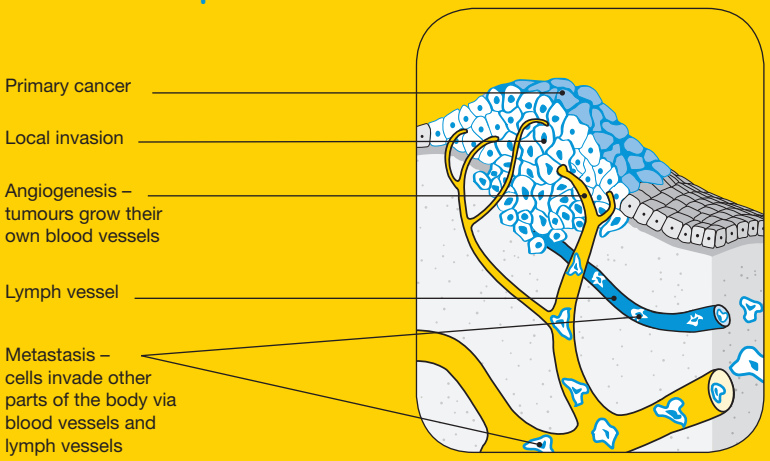
Malignant or invasive cancer

is called the primary cancer. 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 spread, becoming invasive cancer.

Cancer cells can spread to other parts of the body by travelling through the bloodstream or lymphatic system. They may continue to grow into another tumour at this new site. This is called a secondary cancer or metastasis.

A metastasis keeps the name of the original cancer. For example, lung cancer that has spread to the bones is still called lung cancer, even though the person may be experiencing symptoms caused by problems in the bones.

How cancer spreads



The lungs

The lungs are the main organs in the body's system for breathing, called the respiratory system. The respiratory system also includes the nose, mouth, windpipe (trachea) and airways to each lung. The airways to each lung are called large airways (bronchi) and small airways (bronchioles).

When you breathe in (inhale), air goes into the nose or mouth, down the trachea and into the bronchi and bronchioles. At the end of the bronchioles, tiny air sacs called alveoli pass oxygen into the blood and collect the waste gas (carbon dioxide). Carbon dioxide is released back into the atmosphere – and removed from the body – as you breathe out (exhale).

The lungs look like two large, spongy cones. Each lung is made up of sections called lobes – the left lung has two lobes and the right lung has three. The lungs rest on the diaphragm, which is a wide, thin muscle that helps with breathing.

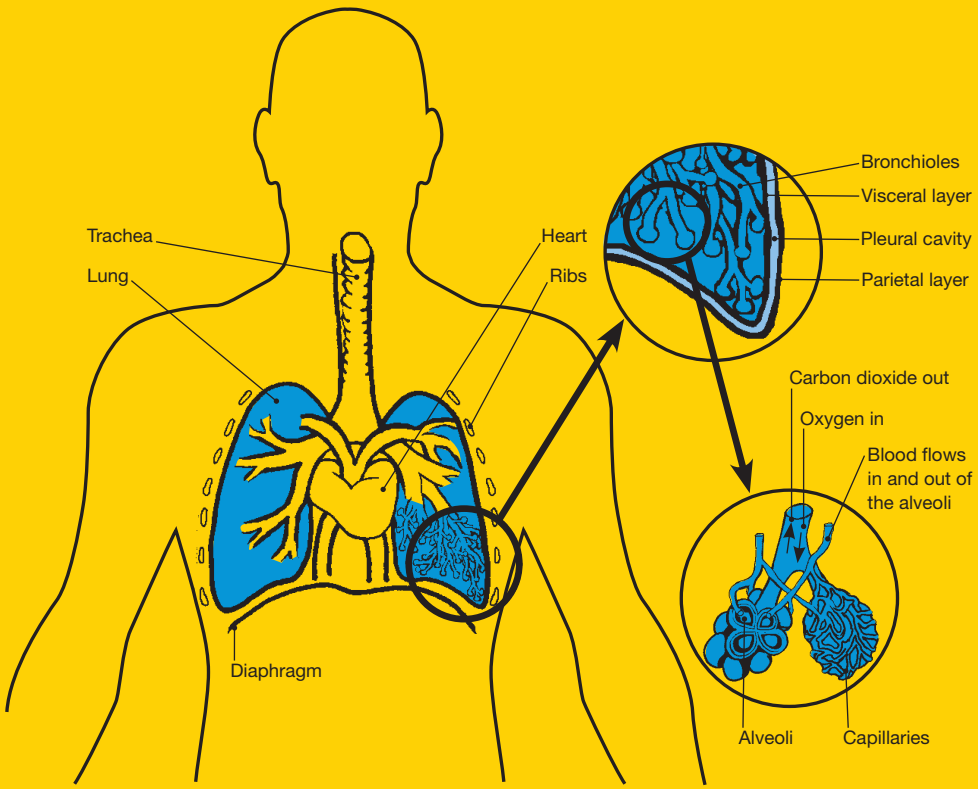
A number of structures lie between the lungs (a space called the mediastinum), including:

- the heart and large blood vessels
- the trachea
- the tube that carries food from mouth to stomach (oesophagus)
- lymph glands (also known as lymph nodes).

The lungs are covered by a thin sheet of tissue called the pleura, which is about the thickness of plastic cling wrap. Its inner layer (the visceral layer) is attached to the lungs and its outer layer

(the parietal layer) lines the chest wall and diaphragm. Between the two layers is the pleural cavity, which normally contains a thin film of fluid. This fluid allows the two layers of pleura to slide against each other so your lungs can move smoothly against the chest wall as you breathe.

The respiratory system



Lung cancer – key questions

Q: What is lung cancer?

A: Lung cancer is a malignant tumour in the tissue of one or both of the lungs.

Some people have primary cancer that started in the lungs. Others have cancer that started somewhere else in the body and spread to the lungs (secondary cancer or metastasis).

Q: What are the different types?

A: There are several types of lung cancer, which are classified according to the type of cell affected.

Non-small cell lung cancer (NSCLC) – Makes up 75–80% of lung cancers. It mainly affects the cells that line the tubes into the lungs (bronchi) and smaller airways. NSCLC is classified as:

- squamous cell carcinoma
- adenocarcinoma, or
- large cell carcinoma.

Small cell lung cancer (SCLC) – Makes up 15–20% of lung cancers. SCLC tends to start in the middle of the lungs, and it usually spreads early. Cancers are named for the way the cells appear when viewed under a microscope. Types include:

- small cell carcinoma (also known as oat cell cancer)
- mixed small cell/large cell carcinoma
- combined small cell carcinoma.

Mesothelioma – A rare type of cancer that affects the protective membrane around the body's internal organs (the mesothelium). Mesothelioma usually affects the pleural membranes around the lungs, but it can also occur in the lining of the abdomen or around the heart.

Mesothelioma is almost always caused by exposure to asbestos, a mineral used in some building materials. In most cases, the development of mesothelioma occurs 25–50 years after asbestos exposure.

Q: How common is it?

A: About 9,200 people (65% males, 35% females) are diagnosed with lung cancer in Australia each year. It is the fifth most common cancer in Australia. Lung cancer is most commonly diagnosed in people 65–79 years old.

Q: What are the causes?

A: Lung cancer is one of the few types of cancer that has a number of known and proven risk factors.

Smoking – About one out of 10 smokers develop lung cancer but studies show that exposure to smoke causes up to nine out of 10 cases of lung cancer.

Breathing in someone else's tobacco smoke (passive or secondhand smoking) can cause lung cancer.

If you are a smoker

Most people started smoking when they were young, at a time when they were unconcerned with – or unaware of – health risks.

Smoking is addictive and this is the main reason smokers continue to smoke even though many people have tried to quit. Your doctors understand this and will consider it when caring for you. They shouldn't regard you negatively because you are (or were) a smoker.

If you need help quitting, call **Quitline** on **13 18 48**.

Non-smokers who have been frequently exposed to secondhand smoke have a 20–30% higher risk of developing lung cancer than non-smokers who have not been exposed. People who have never smoked and have not been around secondhand smoke have a 0.5% risk of getting lung cancer.

Exposure to asbestos – Although the use of asbestos has been banned nationally since 2003, it may still be in some older buildings. People who are exposed to asbestos have a greater risk of getting cancer. Some people are exposed to asbestos at work or during home renovations.

Exposure to other elements – Contact with the processing of steel, nickel, chrome and coal gas may also be a risk factor. Exposure to radiation and other air pollution, such as diesel fumes, also increases the risk of lung cancer.

Q: What are the symptoms?

A: The main symptoms of lung cancer are:

- a new dry cough or change in a chronic cough
- chest pain or breathlessness
- repeated bouts of pneumonia or bronchitis
- coughing or spitting up blood.

Lung cancer is often discovered when it is advanced. It is sometimes detected during routine tests. A person may have experienced symptoms such as fatigue, weight loss, hoarseness or wheezing, difficulty swallowing, or abdominal and joint pain.

Having any one of these symptoms does not necessarily mean that you have cancer. Some of these symptoms may be caused by other conditions or by side effects of smoking. Talk to your doctor to have symptoms checked.

> “I smoked in the past, but I had quit. I just kept having continual colds and I started coughing up blood.”
>
> *Patient*

Diagnosis

Your doctors will perform a number of tests to confirm your diagnosis and develop a treatment plan. Some of these tests can also show if the cancer has spread to other parts of your body.

Chest x-ray

This x-ray is a painless scan of the chest that can show tumours 1 cm wide or larger. Small, hidden tumours don't always show up on x-rays, so you may have further tests.

CT scan

A CT (computerised tomography) scan uses x-ray beams to take three-dimensional pictures of the inside of your body. CT scans are usually done at a hospital or a radiology service and can be used to identify smaller tumours than those found by x-rays. They can also show enlarged lymph nodes or tumours in other parts of the body.

You may be asked not to eat or drink for a few hours before the CT scan. An iodine contrast dye also may be injected into a vein in your arm to make the scan pictures clearer.

A CT scan is painless and takes about 10 minutes. You will lie on a table that slides in and out of a large, round scanner.

Before the scan, tell your health care team if you are allergic to iodine, fish or dyes.

PET scan

A PET (positron emission tomography) scan is a specialised imaging test that is available at some major hospitals. It is useful in diagnosing lung tumours where a biopsy is not possible or inconclusive. A PET scan can also be used to stage lung cancer (see page 17) or find cancer that has spread to other parts of the body.

You will be injected with a radioactive glucose solution. It takes 30–90 minutes for the fluid to go through your body, then you will have a body scan. The scan shows 'hot spots' in the body where the fluid has accumulated – this happens where there are active cells, like cancer cells.

> "I had a PET scan and they could tell that the cancer was only in the right lung and one lymph node nearby."
>
> *Patient*

Sputum cytology

A sputum cytology test is an examination of liquid phlegm or mucus from your lungs (sputum).

You may be asked to collect sputum samples each morning at home. You can collect a sample by coughing deeply and forcefully. Collect any sputum that you cough up and store the sample in your fridge until you bring it to your doctor, who will check for abnormal cells.

Fine-needle aspiration

Your doctor may be able to do a fine-needle aspiration biopsy. Only some tumours, like those in the outer parts of the lungs, can be sampled this way.

The doctor will use an x-ray machine to insert a needle through your chest wall into the tumour. A small piece of tumour can usually be removed with the needle.

The fine-needle aspiration is done in a hospital or radiology department. You will be observed for a few hours afterwards because there is a small risk of the lung being punctured during this procedure.

Bronchoscopy

A bronchoscopy allows the doctor to look directly into the airways (bronchi). You will probably be given a light sedative. A local anaesthetic will also be sprayed on the back of your throat to numb it.

The doctor will insert a flexible tube called a bronchoscope through your nose or mouth and down your windpipe (trachea). The bronchoscope may feel uncomfortable, but it shouldn't feel painful.

During the bronchoscopy, the doctor will take a tissue sample (biopsy). If the tumour is near your main respiratory tract, the cells can be sampled using a technique called brushing

and washing. 'Washing' means that a small amount of fluid is injected into the lung and withdrawn for examination. 'Brushing' is when the doctor uses a brush-like tool to remove some cells from the bronchi.

> "I think the doctors knew I had lung cancer based on the shadow on my CT scan. But they didn't tell me right away. I had to wait two weeks until I had a bronchoscopy and wash." *Patient*

Endobronchial ultrasound

An endobronchial ultrasound (EBUS) is a type of bronchoscopy procedure that allows the doctor to examine the airways (bronchi) and take tissue samples through the airways and windpipe (trachea). Samples may be taken from an adjacent tumour or lymph node.

The doctor will use a bronchoscope with a small ultrasound probe on the end. The bronchoscope will be put down your throat into your trachea. The ultrasound probe uses soundwaves to create a picture of the body and measure the size and position of the tumour.

After an EBUS, you may have a sore throat or cough up a small amount of blood. Tell your medical team how you are feeling so they can monitor you.

Mediastinoscopy

A mediastinoscopy is a procedure that allows a surgeon to examine and sample lymph nodes at the centre of your chest. A rigid tube is inserted through a small cut in the front of your neck and passed down the outside of your trachea. The surgeon will inspect the area between the lungs (mediastinum) and remove some tissue. This is usually a day procedure but some people need to say overnight in hospital.

Thoracotomy

A thoracotomy is an operation performed under a general anaesthetic. It is usually done if other tests fail to provide a diagnosis. Your surgeon will do this test to take a tissue sample (biopsy) or remove the tumour.

The operation can be done in two ways. The surgeon may be able to make some small cuts in your chest and insert a camera and surgical instrument called a thorascope. If this isn't possible, the surgeon will open the chest cavity through a larger cut on your back. You will probably stay in hospital for a few days while you recover.

Further tests

You may also have some other tests, like blood and breathing tests, and bone, brain or MRI scans. For information, talk to your doctor or call the **Cancer Council Helpline** on **13 11 20**.

Staging lung cancer

Your doctor will assign a stage to describe the size of the cancer and if it has spread. This helps determine the best treatment.

Non-small cell lung cancer	
Stage 1	Only one lobe of the lung is affected.
Stage 2	The tumour has spread to nearby lymph nodes, or the tumour has grown into the chest wall.
Stage 3A	Tumours have spread to lymph nodes in the centre of the chest (mediastinum).
Stage 3B	Tumours have spread more extensively to lymph nodes in the mediastinum, there is a collection of fluid in the pleural space around the lung, or there are tumours in more than one lobe.
Stage 4	The cancer cells have spread to distant parts of the body, such as the bones or liver.

Small cell lung cancer	
Limited disease	The tumour can be found in only one lung and nearby lymph glands.
Extensive disease	The tumour has spread outside one lung or to other parts of the body.

Mesothelioma	
Stage 1	Only one side of the chest is affected. The cancer isn't in the chest wall or lymph nodes.
Stage 2	The chest wall, oesophagus, heart or lymph nodes in the chest are affected.
Stage 3	The cancer has spread through the diaphragm into the abdomen, or to lymph nodes in other parts.
Stage 4	The cancer has spread to distant parts of the body.

Prognosis

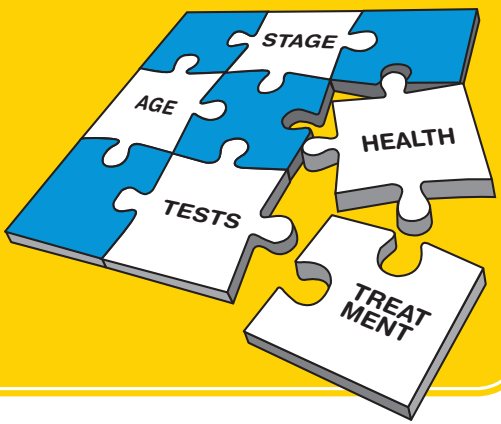
When doctors talk to you about your prognosis, they are telling you about your chance of getting better and talking about expected outcomes of the disease.

You will need to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of your illness. Instead, your doctor can give you an idea about common issues that people with the same type of cancer experience.

As in most types of cancer, the results of lung cancer treatment are best when the cancer is found and treated early. People operated on in the early stages of lung cancer have the best chance of cure. See page 17 for more information about staging lung cancer.

Assessing prognosis

Test results, the type of cancer you have, the rate and depth of tumour growth, how well you respond to treatment, and other factors such as age, fitness and medical history are all important factors in assessing your prognosis.



Jenny's story

I had been having frequent chest colds and in June, I coughed up blood into the toilet. My daughter insisted that I go to hospital.

After having several different types of scans, I was diagnosed with lung cancer. Within a week I had a pneumonectomy to remove my right lung. The surgeon said he got all the cancer but I needed to have chemotherapy to be sure it was gone completely.

Chemo was horrible. I was so sick that I had to stay in hospital for three weeks. When it was over, I was glad. It took me about a year after chemo to really feel well again.

Now I have good and bad days. I do breathing exercises during rehabilitation and take vitamins to stay well. Sometimes I feel so good that I overdo it. I forget that I have one lung and I tire easily. I'm learning to pace myself.

Which health professionals will I see?

Often 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 lung specialist. This specialist will arrange further tests and advise you about treatment options.

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This multidisciplinary team will meet regularly to discuss the most appropriate treatment plan for you.

The team will probably include:

respiratory physician	helps diagnose and stage the cancer and determine initial treatment options
cardiothoracic (chest) surgeon	does some diagnostic tests and performs surgery
medical oncologist	responsible for chemotherapy and following treatment options
radiation oncologist	responsible for radiotherapy
nurses and cancer nurse coordinators	support and assist you through all stages of your treatment
palliative care doctors and nurses	work closely with the GP and oncologist to provide palliative care (see page 30)
dietitian	recommends an eating plan for you to follow while you are in treatment and recovery
speech pathologist	helps with communication and swallowing
social worker, physiotherapist, clinical psychologist and occupational therapist	advise you on support services, help you get back to normal activities and give guidance if you have any emotional, physical or practical problems.

Key Points

- There are many different types of tests to diagnose lung cancer. Different tests are available in different hospitals. You probably won't have every test available.
- Scans and tests can help show if the lung cancer has spread. They can also help your medical team decide on the best treatment plan.
- X-rays, CT scans and MRI scans are painless scans that will take pictures of the inside of your body.
- If you are coughing up phlegm, your doctor might ask you to store it and send it in to a lab to for testing (sputum cytology).
- Sometimes the doctor can insert a needle into your chest to get a sample of tissue. This is called a fine-needle aspiration.
- A bronchoscopy is when a flexible tube is inserted through your nose or mouth and down your trachea to examine your airways.
- Some people have further tests (such as a blood test, PET scan, brain scan, bone scan, mediastinocopy or thoractomy).
- The doctors will assign a stage to your cancer based on diagnostic tests. This describes the size of the cancer and if it has spread.
- Your doctor may talk to you about your prognosis. This is a general prediction about what may happen to you. No one can predict the exact course of your illness.
- You will probably see many doctors who will work together as a multi-disciplinary team to diagnose and treat you.

Treatment

Your choice of treatment depends on the stage of the cancer, your general health and breathing capacity, and your wishes.

- **Non-small cell lung cancer** can be treated with surgery, radiotherapy or chemotherapy.
- **Small cell lung cancer** is usually treated with chemotherapy. Some people with cancer in one lung (limited disease) will have radiotherapy to the chest and brain (called preventive or prophylactic radiotherapy). Because it usually spreads early, surgery is not often used for this type of cancer.
- **Mesothelioma** is rarely able to be removed by surgery. However, people commonly have other types of treatment, such as chemotherapy or thoracentesis, to slow down progression of the disease or to help manage symptoms (see page 30).

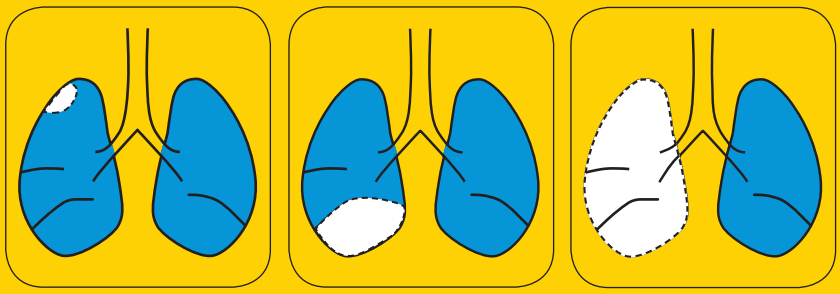
Research shows that quitting smoking will improve your chances of responding to treatment. If you smoke, your medical team will probably tell you to stop smoking before you have an operation.

Surgery

Surgical removal of a tumour offers the best chance of a cure for patients who have early-stage cancer (see page 17). The multidisciplinary team will look at whether or not the cancer has spread beyond the lungs, your general well-being and fitness, and your breathing capacity. They will see if you would be fit enough for surgery and decide if it is an option for you.

Types of lung surgery

There are several types of lung surgery.



Wedge resection: only part of the lung, not a lobe, is removed

Lobectomy: a lobe of the lung is removed

Pneumonectomy: one whole lung is removed.

If the cancer has spread, or if you have mesothelioma in your abdomen, you may have another type of surgery.

After an operation

After major lung surgery you will have an intravenous (IV) drip for at least a few days (though you will be able to eat and drink the day after the operation). There will be one or two temporary tubes in your chest or abdomen to drain fluid and/or air from your chest cavity.

You will have some pain and discomfort but your medical team will work with you to reduce these effects. There is no need to suffer in silence – tell your doctor or nurse how you are feeling. This is important because if you are not in pain, you are more

> The physio came regularly to help me get up after surgery. Eventually the physio walked me around the room. By the end of the last day in hospital, I could walk around the room myself. *Patient*

likely to move around and do exercises with the physiotherapist. Pain-relief may also help you clear phlegm from your chest and reduce your chances of developing a chest infection.

You will probably go home 4–10 days after the operation but you will still be recovering for about six weeks. The recovery time depends on the type of operation and your fitness.

Many patients who have part of their lung removed experience some breathlessness. If your lung function was poor before surgery, or if you have one whole lung removed (pneumonectomy), you may feel very breathless.

Your doctor, nurses and physiotherapist will talk to you about how to manage at home. For example, they might recommend you do regular light exercise, like walking, to speed your recovery. Some people go to rehabilitation to improve their breathing over time.

You will have regular chest x-rays to check your lung or lungs are working properly.

Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. The aim of chemotherapy is to kill cancer cells while doing the least possible damage to healthy cells.

Chemotherapy is commonly given to patients whose cancer is large or has spread outside the lungs. It may be given:

- before surgery, to try to shrink the cancer and make the operation easier
- before radiotherapy or during radiotherapy (chemoradiation), to increase the chance of the radiotherapy working
- after surgery, to reduce the chances of the cancer coming back
- as palliative treatment, to reduce symptoms, improve your quality of life or extend your life (see page 30).

Generally, chemotherapy is administered intravenously through a drip or a plastic catheter (tube) inserted into a vein in your arm, hand or chest. Some types of chemotherapy are given orally, in tablet form.

Chemotherapy is given in cycles that typically last three weeks each. Intravenous chemotherapy may be given for a few days. The rest of the time is a break from treatment. The number of treatments you have will depend on the type of lung cancer you have and how well your body is handling the side effects. You may be able to have treatment as an outpatient.

If you have tablet chemotherapy it will probably be given on a continuous basis.

Targeted therapies

Some types of chemotherapy called targeted therapies may be available. Targeted treatments aren't as harmful to healthy cells.

Your doctor will send a sample (biopsy) of your tumour to the lab to see what types of cells are there. If the cells have a specific gene mutation, your doctor may have to do another biopsy to get more tissue.

Some cancer cells have receptors on their surface. This means the cell wall is shaped in a certain way. Receptors can be a target for chemotherapy drugs. For example, a person with adenocarcinoma might have an epidermal growth factor receptor (EGFR) gene mutation, so the doctor may prescribe targeted therapies for EGFR.

You may be asked if you want to participate in a clinical trial to receive targeted therapy (see page 34). Talk to your doctor for more information about new drug trials.

Side effects

Most drugs used in chemotherapy cause side effects. Different drugs have different side effects – your doctors and nurses will discuss this with you. The most common side effects include:

- nausea, vomiting
- mouth ulcers
- fatigue
- thinning or loss of hair
- skin rashes.

Talk to your medical team if you have side effects – in most cases drugs can be prescribed to make any side effects you experience less severe.

For more info on chemotherapy treatment and its side effects, call the Cancer Council Helpline on 13 11 20 for a free copy of *Understanding Chemotherapy*.

Chemotherapy temporarily weakens your immune system, so you may have trouble fighting infections like the cold or flu. If you have a high temperature (38°C or above) while receiving chemotherapy, seek medical advice immediately.

Radiotherapy

Radiotherapy treats cancer by using x-ray beams to kill cancer cells. It can be given to treat lung cancer that hasn't spread outside the chest or to treat a tumour that is too large for surgery. Radiotherapy can also be used to treat cancer that has spread to the lymph nodes. This may stop the cancer from spreading further or from returning later.

It can also be given:

- after surgery, to reduce the chances of the cancer coming back and to treat cancer that has spread
- before surgery, to shrink a tumour
- as palliative treatment, to reduce symptoms, improve your quality of life or extend your life (see page 30).

To plan radiotherapy treatment, your doctor will take an x-ray or CT scan of the treatment area. To ensure that the same area is treated each time, the radiation therapist will make a few small marks on your skin.

During treatment, you will lay on a treatment table. A machine that delivers the radiation will be positioned around you. The treatment session itself will take about 10–15 minutes. Radiotherapy treatment is painless and the person giving you the treatment will make you as comfortable as possible.

For more information, call the Cancer Council Helpline on 13 11 20 for a free copy of *Understanding Radiotherapy.*

Side effects

The side effects from radiotherapy depend on the area of your body being treated and the dose of radiation.

People who have radiotherapy to the chest for a primary lung cancer may experience tiredness and a mild burn on the skin, like a sunburn. Some patients who have a long course of radiotherapy (several weeks) may have temporary difficulty and pain in swallowing (oesophagitis).

Any radiotherapy to the lungs will cause some scarring, which can be seen on x-rays or CT scans after treatment. Some patients experience shortness of breath for months or years after the radiotherapy has finished. This often happens to people who have a large tumour or another condition like emphysema.

Talk to your health care team for more information about side effects, or call the Cancer Council Helpline on 13 11 20.

Thoracentesis (pleural tap)

When fluid builds up in the area between the lung and the chest wall (pleural space), you may have symptoms like breathlessness, tiredness and pain. Your doctor can relieve the symptoms by performing a procedure called thoracentesis (pleural tap).

In this procedure your doctor inserts a hollow needle between your ribs to drain the fluid out. This will take about 30–60 minutes. A pleural tap is performed under a local anaesthetic and it is usually done on an outpatient basis.

Pleurodesis

Fluid between your lungs and chest wall may re-accumulate after you have a pleural tap. Your surgeons may perform another thoracentesis, but if the fluid continues to build up you may have pleurodesis.

In pleurodesis, you will have an injection of talcum powder between the layers of your lung tissue (pleura). The powder will inflame the membranes and make them stick together. This closes the space between the pleura, preventing the fluid from coming back. You will have a general anaesthetic during the pleurodesis, and you will probably stay in hospital for about three days.

Palliative care

Palliative care helps to improve people's quality of life by alleviating symptoms of cancer without trying to cure the disease.

Palliative care often involves pain relief, stopping the spread of cancer and symptom management. Treatment may include radiotherapy, chemotherapy or other medication. It also involves the management of other physical and emotional symptoms and practical problems. This may include counselling, respite care, physiotherapy and modifications to your house (e.g. installing a ramp).

Although palliative care is particularly important for people with advanced cancer, it is not just for people who are about to die. Palliative care can be used at different stages of cancer.

Call the Cancer Council Helpline on 13 11 20 to request free information about palliative care and advanced cancer.

"I went to a palliative care centre and I had a gentle massage for lymphatic drainage. They said it was to wake up my lymph nodes. It was a feathery touch from my groin to my toes to help move the fluid away." *Patient*

Key Points

- There are many types of lung cancer treatment. Your treatment will depend on your type of cancer, its stage and what is available. It will also depend on your general fitness and breathing capacity.
- If you smoke, quitting will improve your chances of responding to treatment.
- If you have surgery you may have a whole lung, lobe or section of the lung removed.
- After surgery you will stay in hospital for several days. You may feel some pain but you will be given medication.
- You may work with a physiotherapist after surgery to try to improve breathing and endurance. Some people continue rehabilitation when they return home.
- Chemotherapy is the treatment of cancer with drugs. Some types of chemotherapy are called targeted therapies – these drugs may be available in clinical trials.
- Most chemotherapy drugs cause side effects such as nausea, fatigue, hair loss and skin rashes. The side effects depend on what kinds of drugs you are given.
- Radiotherapy treats cancer by using x-ray beams to kill cancer cells. It is painless but it may cause burning on the skin, scarring or shortness of breath.
- If fluid builds up on the lungs, your doctor will drain it so you can breathe easier (thoracentesis or pleurodesis).
- Palliative care is treatment that helps improve quality of life without trying to cure the cancer. It can be used at different stages.

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 will need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, particularly those that affect your lifestyle.
- If you have a partner, you may want to talk about your treatment options with them. You can also talk to your 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 will choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects so they have the best possible quality of life. Some people may choose options that don't try to cure the cancer but make them feel as well as possible for as long as possible.

Talking with doctors

When your doctor first tells you that you have cancer, it is very stressful and you may not remember many details about what you are told. 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 47).

Before you see the doctor, it may help to write down your questions – see the list of suggested questions on page 46. 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.

If you have several questions for your doctor, you may want to book a longer appointment.

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 your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You 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. Over the years, clinical trials have improved cancer treatment standards and led to better outcomes for patients.

Many new treatments for lung cancer, including some types of targeted therapies (see page 26), are only available in clinical trials.

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 part of a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your treatment for cancer. If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

For more information about clinical trials – such as questions to ask your doctor and how to find a trial that is suitable for you – call the Helpline on 13 11 20.

Looking after yourself

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 to 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 foods for your situation. The Cancer Council Helpline can send you information about nutrition.

Being active

You will probably find it helpful to stay active if you can. Physical activity – even if gentle or for a short time – may help to improve circulation, reduce tiredness and elevate mood.

The amount and type of exercise you do will depend on what type of treatment you have had, what you are used to, your breathing capacity and what your doctor advises.

> “Since the operation, I’ve done breathing exercises. I went to rehab at the local hospital and did exercise bikes. At first I couldn’t do the six-minute walk, but I worked up to walk ¾ kilometre.” *Patient*

Complementary therapies

Complementary therapies are treatments that 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. Some therapies may not be appropriate, depending on your conventional treatment. For example, herbs and nutritional supplements may interact with your medication. Massage and exercise therapies may also need to be modified. Call the Helpline on 13 11 20 for more information about complementary therapies.

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.

Relationships with others

The strong emotions you experience as a result of cancer may affect your relationships. Your experiences may cause you to make some changes in your life or 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 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 may help to discuss how you both feel about the situation.

> "The whole time I was on chemotherapy and radiotherapy, my friend called me everyday between 8–9am. She could hear if I was well by my voice. There aren't many friends like that around." *Patient*

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**.

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 hair loss, weight changes and other physical changes, call the Cancer Council Helpline.

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 treatment and side effects, and your self-confidence. Knowing the potential challenges and addressing them will help you adjust.

Some people with cancer have the support of a partner, but others are single. You may choose not to be in a monogamous or long-term relationship, or you may be searching for a partner. It can be difficult to bring up cancer with a new partner.

Sexual intercourse may not always be possible during treatment, but if you are in a relationship, you can try to maintain closeness and emotional intimacy.

Call the Helpline on 13 11 20 to request more information about sexuality and cancer.

Contraception

If you have certain types of treatment, such as chemotherapy, you may be advised to use contraception or abstain from sex for 48 hours after treatment. This is to protect your partner from chemicals that may be in your body fluids. Talk to your medical oncologist or nurse for more information.

If you want to conceive a baby, ask your doctor for advice. Women should not become pregnant during the course of chemotherapy. The type of birth control you use will depend on what you and your partner are comfortable using. Your doctor can give you advice about the best birth control for you.

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.

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. Many cancer survivors say they don't necessarily return to 'normal life' as it was before cancer. Instead, it takes some time to establish a 'new normal'.

Different people find different approaches help them. 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
- tell your family and friends how to support you
- talk to someone else who has had 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 and/or medication may help you.

Seeking support

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 43
- 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. This can be difficult, and it may make you feel lonely. Cancer Council has information about coping with your emotions – call the Helpline on 13 11 20 to ask for a free copy.

If you have children, the prospect of telling them you have cancer can be frightening and unsettling. Talking to a health professional or social worker may 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 may be 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.

Learning more about cancer

If you want to find out more about cancer and how to cope with it, ask your local Cancer Council or hospital about education programs or seminars available.

Programs may cover topics such as what cancer is, treatment, side effects and support services. Attending a program will also give you an opportunity to meet other people affected by cancer.

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 or call the Helpline on 13 11 20.

Support services available in your community

- **Support groups**
  held in community centres, hospitals or over the phone
- **Online discussion forums**
  see www.cancerconnections.com.au
- **Personal support**
  talk to someone else who has been through cancer treatment.

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.

Support services such as 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. To learn more, contact Carers Australia on (02) 6122 9900 or www.carersaustralia.com.au.

Call the Cancer Council Helpline to find out more about different services or to request free information for carers.

Cancer Council library

Following a cancer diagnosis many people look for information about treatment, the latest research findings and stories about how other people have coped. The Cancer Council has a range of books, CDs, DVDs and medical journals that may be helpful for you.* Your local library may also have some relevant resources.

*This service is not available in Victoria and Queensland.

Lung Cancer: Understanding, Managing, Living is a DVD with information for people with lung cancer. Visit **www.kjlcn.org.au** or call **1800 654 301** to request a free copy.

Useful websites

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

Australian

Your local Cancer Council

Australian Capital Territory ..... **www.actcancer.org**
New South Wales ..... **www.cancercouncil.com.au**
Northern Territory ..... **www.cancercouncilnt.com.au**
Queensland ..... **www.cancerqld.org.au**
South Australia ..... **www.cancersa.org.au**
Tasmania ..... **www.cancertas.org.au**
Victoria ..... **www.cancervic.org.au**
Western Australia ..... **www.cancerwa.asn.au**

National health websites

Cancer Council Australia..... **www.cancer.org.au**
Cancer Voices Australia..... **www.cancervoicesaustralia.org.au**
Health Insite..... **www.healthinsite.gov.au**

Lung cancer-specific websites

The Australian Lung Foundation ..... **www.lungfoundation.com.au**
Kylie Johnston Lung Cancer Network..... **www.kjlcn.org.au**
Asbestos Diseases Foundation..... **www.adfa.org.au**

International

American Cancer Society..... **www.cancer.org**
Macmillan Cancer Support ..... **www.macmillan.org.uk**
US National Cancer Institute ..... **www.cancer.gov**
Mesothelioma Cancer Center..... **www.asbestos.com**

Question checklist

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

- What type of lung cancer do I have?
- How extensive is my cancer?
- What do you think my prognosis is?
- What treatment do you recommend and why?
- Are the latest tests and treatments for my type of cancer available in this hospital?
- Are there other treatment choices for me? If not, why not?
- Are there any clinical trials of new treatments?
- 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 much will treatment affect what I can do?
- Will the treatment affect my sex life?
- Would palliative care be useful for me?
- Are there any complementary therapies that might help me?
- How frequently will I have checkups?

Glossary

adenocarcinoma
A cancer that starts in the glandular tissue.

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.

alveoli
The tiny air sacs in the lungs, where oxygen enters the blood and carbon dioxide leaves it.

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 person to lose consciousness for a period of time.

asbestos
A naturally occurring mineral that forms long, crystallised fibres. Formerly used in manufacturing and building, asbestos use is now banned in Australia because its fibres can cause serious illness.

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

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

bronchiole
A small passage that carries air into the outer parts of the lungs.

bronchiolo-alveolar cell carcinoma
A type of non-small cell lung cancer.

bronchoscopy
A diagnostic test to examine the lungs and respiratory system.

bronchus/bronchi
Tubes in the respiratory system that carry air into the lungs.

catheter
A hollow, flexible tube through which fluids can be passed into the body or drained from it.

cells
The basic organisational unit of

all living things. A human is made of billions of cells, which are adapted for different functions.

chemoradiation
Treatment that combines chemotherapy with radiotherapy.

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

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.

emphysema
A benign condition in which the alveoli of the lungs are enlarged and damaged. It reduces the lung's surface area, causing breathing difficulties.

fine-needle aspiration
A biopsy procedure in which a fine needle is inserted into a lump to extract cells.

intravenous (IV)
Inserted into a vein.

lobe
A section of an organ. For example, the left lung has two lobes and the right lung has three lobes.

lobectomy
A surgical operation to remove a lobe of a lung.

lungs
The two spongy organs in the chest cavity, made up of large numbers of tiny air sacs. The lungs are used for respiration (breathing).

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

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.

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

mediastinoscopy
A surgical procedure that allows a surgeon to examine the lymph nodes at the centre of the chest and remove a sample, if necessary.

mediastinum
The area in the chest between the lungs. It contains the heart and large blood vessels, the oesophagus, the trachea and many lymph nodes.

mesothelioma
A type of cancer that affects the protective membrane around the internal organs (mesothelium). It often occurs in the membranes of the lungs (pleura).

metastasis
A cancer that has spread from another part of the body. Also known as secondary cancer.

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

non-small cell lung cancer
One of the two main groups of lung cancers. Includes squamous cell carcinoma, adenocarcinoma and large cell carcinoma.

oesophagus
The tube that carries food from the throat into the stomach. Sometimes called the gullet.

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

palliative care
The holistic care of people who have a life-limiting illness, their families and carers. It aims

to improve quality of life by addressing physical, emotional, spiritual, social and practical needs. It is not just for people who are about to die, although end-of-life care is a part of palliative care.

parietal layer

The outer layer of the pleura (lungs).

PET scan

A positron emission tomography scan. A specialised imaging test that uses a radioactive glucose solution to identify cancer cells in the body.

pleura

Membranes that line the chest wall and cover the lungs.

pleural cavity

The space that lies between the two layers of the pleura (lungs) and normally contains a thin film of fluid.

pleural effusion

An abnormal build-up of fluid in the pleural cavity (lung area).

pleural tap

See thoracentesis.

pleurodesis

An injection between the layers of the lung tissue (pleura). This injection creates an inflammation that closes the space between the pleura. This prevents accumulation of fluid.

pneumonectomy

A surgical operation to remove a lung.

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.

prognosis

The likely outcome of a person's disease.

radiotherapy

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

resection

Surgical removal of a portion of any part of the body.

respiratory system
The system of the body responsible for breathing.

small cell lung cancer
A type of lung cancer strongly associated with cigarette smoking. It spreads early and causes few initial symptoms.

sputum
Liquid coughed up from the lungs. Also known as phlegm.

sputum cytology test
Examination of sputum under a microscope to look for cancer cells.

squamous cell carcinoma (SCC)
A cancer that arises in the squamous or skin-like cells of the body.

staging
Performing tests to determine how far cancer has spread.

thoracentesis
A procedure in which doctors insert a hollow needle between the ribs in order to drain excess fluid. Also called a pleural tap.

thoracotomy
A type of surgery. The surgeon opens the chest cavity through a cut on the back and examines, biopsies and/or removes the tumour.

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

trachea
The windpipe. The trachea is the airway that brings air inhaled from the nose and mouth into the lungs.

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

visceral layer
The inner layer of the pleura.

wedge resection
Surgery to remove part of a lung, but not a complete lobe.

How you can help

At Cancer Council we're dedicated to defeating cancer. As well as funding cancer research, 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. 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 retail stores: Every purchase 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.

Join a research study: Cancer Council does research to investigate the causes, management, outcomes and impacts of different cancer types.

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

Cancer Council Helpline 13 11 20

Monday to Friday 9am to 5pm

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

For the cost of a local call, you, your family, carers or friends can talk about any 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.

If calling outside business hours, you can leave a message and your call will be returned the next business day.

Cancer Council Publications

Treatments and side effects

- Chemotherapy
- Radiotherapy
- Clinical Trials
- Complementary Therapies
- Palliative Care
- Massage and Cancer

Coping with cancer and recovery

- Food and Cancer
- Emotions and Cancer
- Caring for Someone with Cancer
- Understanding Your Rights
- Overcoming Cancer Pain (book & DVD)
- Talking to Kids About Cancer
- Sexuality, Intimacy and Cancer
- Living with Advanced Cancer
- Cancer Support Groups
- Cancer Care Diary
- Living Well After Cancer
- Relaxation CD
- Mindful Meditation CD

Types of cancer

Cancer Council publishes booklets with information on more than 20 types of cancer.

How to request free copies

Free copies are available from your local treatment centre or by calling the Helpline on **13 11 20**.

You can also download them from **www.cancercouncil.com.au.**

Cancer Council Helpline 13 11 20

Cancer Council NSW

REGIONAL OFFICES

Central & Southern Sydney Region
Woolloomooloo
Ph: (02) 9334 1900

Far North Coast Region
Alstonville
Ph: (02) 6627 0300

Hunter Region
Broadmeadow
Ph: (02) 4923 0700

Mid North Coast Region
Coffs Harbour
Ph: (02) 6659 8400

North West Region
Tamworth
Ph: (02) 6763 0900

Northern Sydney and Central Coast Erina Region
Ph: (02) 4336 4500

South West Region
Wagga Wagga
Ph: (02) 6937 2600

Southern Region
Wollongong
Ph: (02) 4223 0200

Western Region
Orange
Ph: (02) 6392 0800

Western Sydney Region
Parramatta
Ph: (02) 9354 2000

The Australian Lung Foundation

"When you can't breathe... nothing else matters"™

Cancer Council Helpline 13 11 20

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**.

Understanding Lung Cancer

JUL 2010 CAN724