

Better Living with Lung Cancer

A Patient Guide



LUNG
FOUNDATION
AUSTRALIA

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

Better Living with Lung Cancer – A Patient Guide

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Enquiries to adapt this material should be addressed by email to enquiries@lungfoundation.com.au

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The International Association for the Study of Lung Cancer (IASLC), *Lung Cancer Guide*

Stinchcombe T. & Socinski M.A., 2011, *Maintenance Therapy in Advanced Non-small Cell Lung Cancer*; *Journal of Thoracic Oncology*, 6:1 174

Women Against Lung Cancer in Europe (WALCE), *Targeted Therapies* booklet

The Sydney Local Health District document, *Preparing for Lung Surgery*

Cancer Council NSW, *Understanding Nutrition*

NPS, *Be Medical Wise* website – www.nps.org.au

Life with Lung cancer website – www.lifewithlungcancer.info

Lung Foundation Australia website – www.lungfoundation.com.au

AIHW & Cancer Australia 2011. *Lung cancer in Australia: an overview*. Cancer series no. 64. Cat. no. CAN 58. Canberra: AIHW

The EGFR website – www.egfr-mutation.com

The Australian Lung Foundation, 2012, *Better Living with Chronic Obstructive Pulmonary Disease*

Cancer Institute NSW – eViQ Cancer treatments Online – www.eviq.org.au

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Overview

Lung Foundation Australia developed this booklet to help people diagnosed with lung cancer understand more about lung cancer, its diagnosis and treatment. You will find information to explain what lung cancer is, its causes, the symptoms and the different types of lung cancer.

There is no routine screening for the early detection of lung cancer in Australia and the disease can be difficult to diagnose. Many different tests are used to diagnose lung cancer, including identifying the type and accurately staging the cancer.

During the diagnosis and treatment of lung cancer, a multidisciplinary team of health professionals cares for you. Each member of this team specialises in different aspects of the treatment regimen and work together to ensure you receive the best care.

The treatment for lung cancer depends on the type and stage of the disease. The main types of treatment are surgery, chemotherapy, radiotherapy and targeted therapies – often a combination of these.

Medical research results in new and improved treatments and taking part in a clinical trial can give you access to the latest treatments. This option is explained so that you understand what a clinical trial is and how you can take part in one if this is an option for you.

The side effects that are common to all lung cancer treatments and those that are specific to each particular treatment regimen are explained in this booklet. You will also find details about how to manage these side effects.

When faced with a diagnosis of lung cancer there are many decisions to be made. You may want a second medical opinion to help you make decisions about treatment at the various stages of the disease. There are also financial and legal considerations that can affect you and your family now and in the future.

Access to palliative and supportive care is an important aspect of the lung cancer journey. So is living well with lung cancer, to enhance your quality of life.

An extensive range of information and resources is available to provide you with as much information as you seek. Support services and patient support groups can help you deal with the range of emotions you're likely to experience and put you in touch with others who are going through similar experiences.

This booklet may be helpful for the person who is your main carer. There is a section included specifically for carers.

At all times, you can contact Lung Foundation Australia for information and support by telephoning **1800 654 301** or by visiting **www.lungfoundation.com.au**.

1. Understanding Cancer and the Lungs

What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks and our bodies are constantly making new cells to help us grow, to replace worn-out cells, or to heal damaged cells after an injury.

Normally cells grow, multiply and die in an orderly way. However, sometimes something goes wrong with the cell cycle process. This can lead to the uncontrolled growth and or survival of abnormal cells, which may develop into a lump called a 'tumour'.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread outside its normal boundary to other parts of the body. However, if a benign tumour continues to grow at the original site, it can cause a problem by pressing on nearby organs.

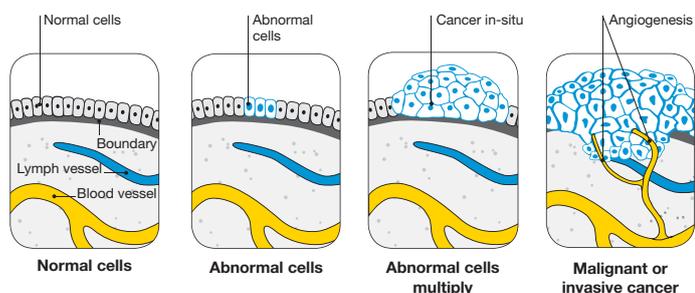
A malignant tumour is a mass of cancer cells growing out of control and capable of spreading to other organs in the body. The tumour is called 'cancer in-situ' or 'localised cancer' if hasn't yet to

spread to nearby tissues. As the tumour grows, it may invade surrounding tissue, becoming invasive cancer.

Cancer cells can spread by travelling through the circulatory system (blood) or the lymphatic system. The lymphatic system is a network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells. When cancer cells reach a new site in the body, they may continue to grow and form another tumour at that site. This is called a 'secondary cancer' or metastasis.

Cancer that starts and grows in the lungs is known as 'primary lung cancer'. Sometimes cancer can spread to the lungs, having started as a 'primary' in another part of the body such as the breast, bowel, or prostate. These cancers are called lung 'secondaries' or 'metastases'. 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 starts



How cancer spreads

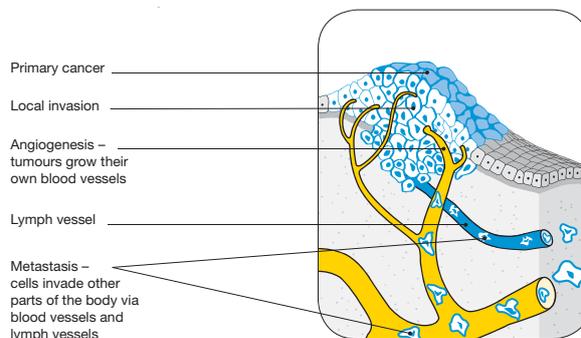


Illustration source: Cancer Council Victoria ©



1. Understanding Cancer and the Lungs

The lungs – their function and anatomy

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 – known as the large airways (bronchi) and small airways (bronchioles).

The respiratory system

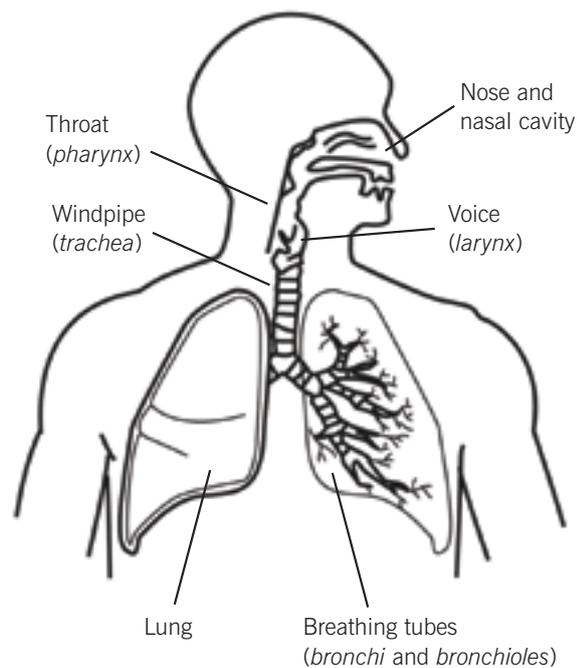
The respiratory system includes the upper and lower respiratory tract.

The upper respiratory tract consists of:

- the nose and nasal cavity;
- the throat (*pharynx*); and
- the voice box (*larynx*).

The lower respiratory tract consists of:

- the windpipe (*trachea*);
- breathing tubes (*bronchi* and *bronchioles*); and
- air sacs (*alveoli*).



The respiratory system

Structure of the lungs

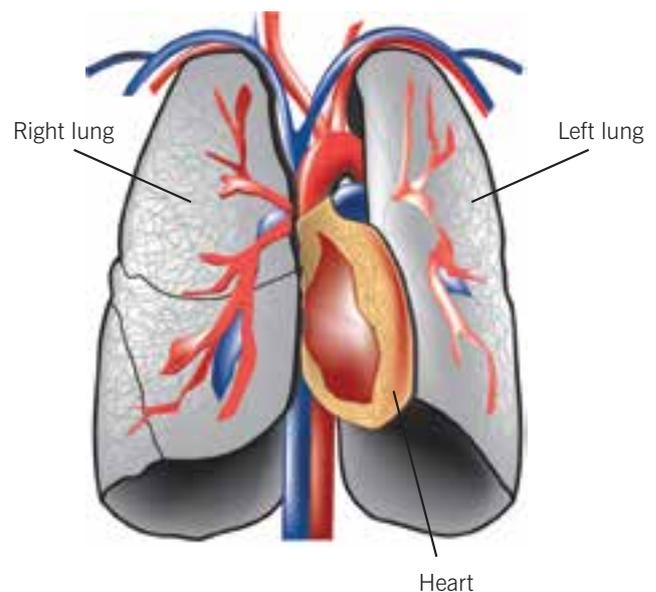
The two lungs are located inside the chest, protected by the ribcage. The lungs are soft and look like two large, spongy cones.

Sections called lobes make up each lung. The left lung has two lobes and the right lung has three. The lungs rest on the diaphragm – a wide, thin muscle that helps with breathing.

Several structures lie in the space between the lungs, called the mediastinum, including:

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

A double layer of thin membrane called the pleura surrounds the lungs. The pleura are 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.

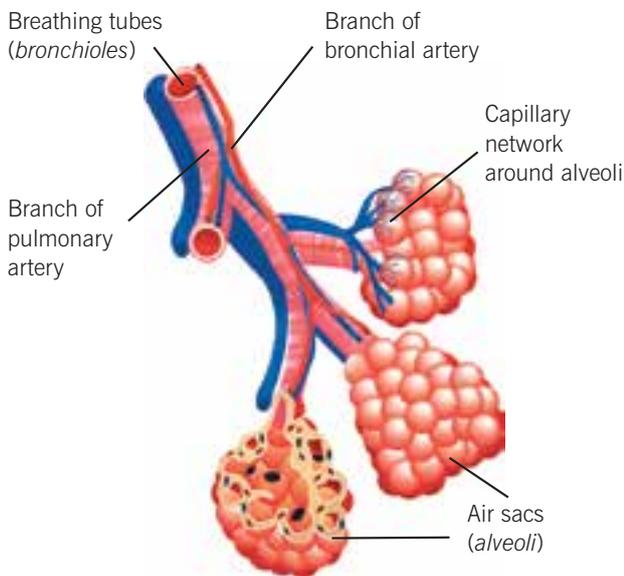


Lung structure

1. Understanding Cancer and the Lungs

Within the lungs is a transport system for oxygen and carbon dioxide. Each time you breathe, you draw air into the windpipe (trachea) via the mouth and nose.

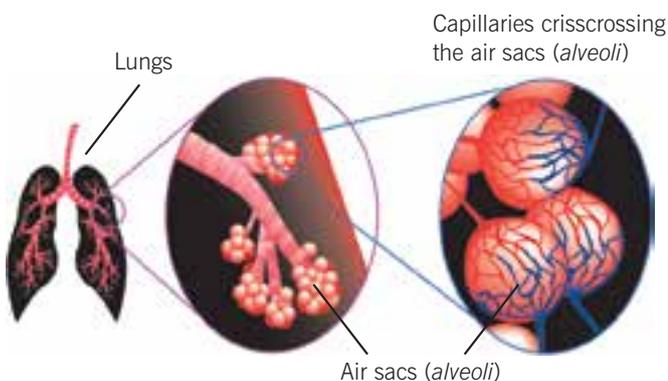
The windpipe splits into two breathing tubes (bronchi) – one to the left lung and one to the right lung. The breathing tubes continue to divide into smaller and smaller tubes (bronchioles), which take air down into each lung.



The Airways

What the lungs do

To survive, your body needs oxygen (O_2) which you get from the air you breathe. The lungs help take oxygen from the air, through the air sacs (alveoli) and into the body. Tiny blood vessels (capillaries) surround the air sacs. The capillaries crisscross the walls of the air sacs.



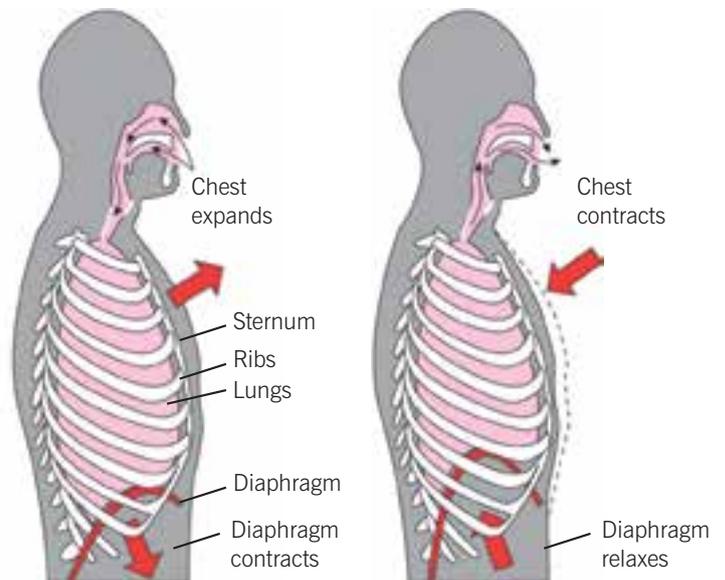
How the lungs function

The air sacs are where oxygen, which is a gas, is absorbed into the bloodstream. Oxygen is then carried along the bloodstream, through the heart, to where it's needed in the body.

Carbon dioxide (CO_2) is a waste product that is produced by the body. Carbon dioxide is a gas that moves from the bloodstream back into the air sacs and through the airways, where it's breathed out.

How you breathe

The lungs are not a muscle and do not move on their own. The diaphragm is the main breathing muscle, when you breathe in, the diaphragm acts like a pump, contracting and moving down. The muscles between the ribs also contract. The lungs expand and draw air into the lungs. When you breathe out, the diaphragm relaxes and moves back up. The muscles between the ribs relax. The lungs reduce to normal size and push air out of the lungs.



Breathing in

Breathing out

1. Understanding Cancer and the Lungs

Lung cancer in Australia*

In Australia, lung cancer is the fourth most commonly diagnosed cancer in both men and women, with more than 9,700 new cases diagnosed each year. However, among our indigenous population, it's the most common cancer in men and the second most common cancer in women.

Tobacco smoking is a major cause of lung cancer with studies showing smoking (or exposure to smoke) causes up to 90 per cent of lung cancers in men and about 65 per cent of lung cancers in women. Environmental factors including occupational exposure to industrial and chemical carcinogens, and indoor and outdoor air pollution also may increase the risk of lung cancer. Other factors are a family history of lung cancer and previous lung cancer disease.

Lung cancer incidence relates strongly to age, increasing sharply after the age of 50 years. (In Australia, only about five per cent of lung cancers are diagnosed in people who are under 50 years of age.) More than 84 per cent of new lung cancers in males and 80 per cent in females are diagnosed in the 60 years plus age group.

“*Cancer is not a death sentence, plenty of people survive it.*”

Michael, 52, a former lung cancer patient

The incidence rate has been decreasing in men but increasing in women over the past 30 years. However, men are still almost twice as likely to be diagnosed with lung cancer as women are, with about 6,000 Australian men and 3,750 women diagnosed with lung cancer annually.

The prognosis for lung cancer has improved in Australia. However, lung cancer remains the leading cause of cancer deaths in both Australian men and women. The highest mortality rates are among indigenous Australians, people living in remote areas and those in the lowest socio-economic status areas. Significantly, Australia's death rate from lung cancer is lower than the rates in North America, Northern Europe and Eastern Asia.

** Based on the 2007 statistics released by the Australian Institute of Health and Welfare.*

Chapter Summary

- ▷ Cancer is a disease of the cells. It can be contained as a 'growth' (tumour) or spread (metastasize) to different parts of the body.
- ▷ The lungs are the body's main organs for breathing and transporting oxygen into the body.
- ▷ More than 9700 new cases of lung cancer are diagnosed each year in Australia, making it the fourth most common cancer in both men and women.

2. Understanding Lung Cancer

Types of lung cancer

Lung cancer is a malignant tumour in the tissue of one or both lungs. There are two different types of lung cancer:

- **Non-Small Cell Lung Cancer (NSCLC)** is the most common and makes up approximately 80 per cent of all lung cancers; and
- **Small Cell Lung Cancer (SCLC)**, which makes up about 20 per cent of lung cancers.

The three main subtypes of NSCLC are adenocarcinoma, squamous cell carcinoma, and large cell carcinoma. The different types of lung cancer are classified according to the type of cell affected, as outlined in the following table.

Type of Lung Cancer	Frequency (among all lung cancers)	Other Features
Non-small cell (NSCLC)	80-85%	The exact type of NSCLC needs to be diagnosed for optimal therapy.
Adenocarcinoma	35-40%	Most common type of lung cancer overall in women and in people who have never smoked.
Squamous cell carcinoma	25-30%	Highly associated with tobacco smoking.
Large cell carcinoma	15%	Can grow rapidly and spread more quickly than other forms of lung cancer.
Small cell (SCLC)	15-20%	These cancer cells multiply rapidly and form large tumours that can spread throughout the body. Current or former smoking is the usual cause.

Mesothelioma

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

Exposure to asbestos, a mineral used in some building materials, is usually the cause of mesothelioma. In most cases, mesothelioma develops 20 to 50 years after asbestos exposure.

While this booklet does not focus on mesothelioma, much of the information will be of benefit to mesothelioma patients.

For more information on mesothelioma, please contact Lung Foundation Australia and request a copy of our Mesothelioma DVD or download from Lung Foundation Australia website: www.lungfoundation.com.au. You can also download Cancer Council Victoria's patient booklet on Mesothelioma by visiting www.cancervic.org.au/downloads/booklets/Mesothelioma.pdf.



2. Understanding Lung Cancer

Causes of lung cancer

Lung cancer results from damage to genes in lung cells. This damage allows cells to grow and divide uncontrollably, eventually spreading throughout the body.

As with many types of cancer, we don't always know the causes of lung cancer. However, there are some known risk factors for developing lung cancer.

From studies, we know that smoking (or exposure to smoke) causes up to 90 per cent of lung cancers in men and about 65 per cent of lung cancers in women. About one in 10 smokers will develop lung cancer, while the risk for people who have never smoked is about one in 200.

Passive or second-hand tobacco smoke can also cause lung cancer. Non-smokers who have been frequently exposed to second-hand smoke have a 20 to 30 per cent higher risk of developing lung cancer than non-smokers who haven't been exposed.

People exposed to asbestos have a greater risk of getting cancer. Although the use of asbestos in Australia was banned in 2003, it still may be present in some older buildings. Some people are exposed to asbestos at work or during home renovations.

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

Symptoms of lung cancer

Like all diseases, the symptoms for lung cancer can vary. However, lung cancer patients often experience the following:

- a persistent chest infection (or a cough that doesn't go away) or if you have asthma, COPD or allergies that predispose you to a cough, you may develop a new or changed cough or wheeze;
- you may notice you've begun coughing up a small amount of blood or the phlegm is streaked with blood (known as haemoptysis);
- breathlessness or a shortness of breath with activity;
- repeated bouts of pneumonia or bronchitis;
- weight loss;
- metastases (or the spread of disease, such as infection or cancer, from one organ to another); and
- low energy levels (fatigue)

You also may be experiencing 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 you have cancer. Some of these symptoms may be caused by other conditions or be side effects of smoking.

Talk to your doctor to have your symptoms checked out. Lung cancer is often discovered when it's advanced and may be detected during routine tests.

See Chapter 5 in this booklet for information on managing the symptoms of lung cancer.

“ As a non-smoker I didn't realise you could get non-smoking related lung cancer. I'd had my cancer for four years before I was diagnosed and wasn't ill. They say it's the silent killer. I was one of the lucky ones ”

Sandy (diagnosed in 2011)

“ I felt completely well. Not one single symptom that made me feel less than 100 per cent. I was walking kilometres every day, eating and sleeping well, and had given up smoking in 1992. [I asked] how could I possibly have lung cancer? ”

Coleen, 60 (diagnosed in 2006)

Chapter Summary

- ▷ Lung cancers fall into two main categories: Non-Small Cell Lung Cancer (NSCLC) – which includes Adenocarcinoma, Squamous cell carcinoma and Large cell carcinoma – and Small Cell Lung Cancer (SCLC).
- ▷ Known risk factors for lung cancer include active and passive smoking; exposure to asbestos, radiation and air pollution; and contact with the processing of steel, nickel, chrome and coal gas.
- ▷ Symptoms for lung cancer vary and include a persistent chest infection or cough, begin coughing up blood, experience shortness of breath, weight loss and/or fatigue.
- ▷ Lung cancer affects everyone – young, old, male, female, smoker or non-smoker.



3. Diagnosing Lung Cancer

Lung cancer is a difficult disease to diagnose and there is no routine screening in Australia for its early detection. For some people, lung cancer is discovered during a routine medical check-up, while others may have had signs and symptoms for many months.

Often your GP arranges the first tests to assess your symptoms. Make sure you discuss all of your symptoms with your doctor so that they can work with you to choose the most useful tests to confirm your diagnosis and help develop a treatment plan. This can be a worrying and tiring time, especially if you need several tests. If these tests don't rule out cancer, it's usual to be referred to a lung specialist who will arrange further tests and advise you about treatment options.

There are many different types of diagnostic imaging and pathology tests used to accurately diagnose and stage lung cancer. The purpose of these tests is to identify the type of lung cancer (NSCLC or SCLC) you have and if the cancer has spread to other parts of your body. Unfortunately, all the tests are rarely located at one centre so some tests may need to be outsourced to other hospitals/centres.

You're likely to see many doctors and together this team of health professionals (called a multidisciplinary team, see Chapter 4) will determine which tests are relevant to your lung cancer. They will organise the tests for you as part of managing your treatment and care.

Diagnostic imaging

Medical imaging involves painless procedures that take pictures of the inside of your body. These scans can show if you have lung cancer and if it has spread. This will help your medical team decide on the best treatment plan for you.

Chest x-ray

An x-ray of the chest is a scan that can show tumours one centimetre 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. CT scans 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. Before the scan, tell your health care team if you're allergic to iodine, fish or dyes.

A CT scan usually takes less than 10 minutes. You will lie flat on a table while the CT scanner – a machine that is large and round like a doughnut – rotates around you.

PET scan

A PET (positron emission tomography) scan is a specialised imaging test that is available at some major hospitals. A PET scan can be used to stage lung cancer (see page 13) or find cancer that has spread to other parts of the body.

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



Diagnostic tests

Pathology

A pathologist can examine tissue samples to identify the type of lung cancer. Their first aim is to confirm, using a microscope, whether they can see cancer cells.

Sputum cytology

If you're coughing up phlegm (sputum), your doctor may ask you to collect phlegm samples at home by coughing deeply. You will be given a container to collect the sample, which you can then store in your fridge until you take it to your doctor. The sample of your phlegm is sent to a laboratory to be tested for cancer cells.

Biopsy

If a growth is found via diagnostic imaging, a sample of the tissue is required to confirm if the growth is cancerous. In this situation, your doctor may request a biopsy. A biopsy involves taking a small sample of tissue from the growth.

A pathologist will examine the tissue under a microscope, and will sometimes perform further tests to determine if the cells are cancerous or benign. There are several procedures for obtaining a biopsy and your doctor will decide which one is right for you.

One of the most frequently requested biopsies for lung cancer is a 'core biopsy' as it is an extremely accurate method of diagnosis. A radiologist uses an ultrasound or CT scan to locate the growth and inserts a small needle through the skin to take a core biopsy sample from the growth. Before he or she performs the biopsy, you will be given a local anaesthetic.

Case Study: Peter's diagnosis

Peter, 54, was stunned when told he had secondary tumours in his spine.

"I went to the doctor with a sore back, it'd been sore for years!" Peter said.

"The next few days were a busy, medical blur – CAT scans, an MRI, a PET scan and a needle biopsy of the spine."

Peter's GP gave him the results: non-small-cell lung cancer – adenocarcinoma of the lung, stage 4. He was told that the median survival time for someone with this type and stage of lung cancer was about a year – with about one per cent of patients living for five years, or more.

Following two years of treatment, including targeted therapy, Peter remains cancer free.



3. Diagnosing Lung Cancer



Before having a biopsy, it's a good idea to discuss the procedure with your doctor. In some cases, there isn't a lot of tissue available to biopsy and this can make the procedure difficult to perform. However, you can plan with your doctor to ensure the initial biopsy yields the best possible information.

Bronchoscopy

A bronchoscopy allows the doctor to look directly into the airways (bronchi) and, if required, biopsy samples of lung tissue.

The procedure is performed using a flexible tube called a bronchoscope, which is inserted through your nose or mouth and down your windpipe (trachea). The bronchoscope may feel uncomfortable, but it should not be painful. You will be given either a light sedation or a general anaesthetic and the back of your throat is numbed with a local anaesthetic.

During the bronchoscopy, the doctor may take a tissue sample if they can see something that looks like cancer. Even if the doctor can't see an obvious tumour they will still take samples if they are suspicious of cancer. Tissue samples may be collected via a biopsy or by 'washing' or 'brushing'.

In washing, saline water is injected through the bronchoscope into the area of interest and suctioned back. This process dislodges cells that can be analysed in the laboratory. Alternatively, a soft brush-like tool can be inserted through the bronchoscope to collect cells from the bronchi by brushing the airway.

Endobronchial ultrasound (EBUS)

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

The doctor uses a bronchoscope with a small ultrasound probe on the end. The bronchoscope is put down your throat into your trachea. The ultrasound probe uses sound waves 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're feeling, so that they can monitor you.

Mediastinoscopy

A mediastinoscopy is a procedure that allows a surgeon to examine and sample the 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 windpipe (trachea). The surgeon inspects the area between the lungs (mediastinum) and removes some tissue.

A mediastinoscopy is usually a day procedure, but an overnight hospital stay may be required. The scar on your neck is usually quite small and will be covered with a dressing.

Thoracotomy

Usually a thoracotomy is done if other tests fail to provide a diagnosis. It's an operation performed by a surgeon, under general anaesthetic, to take a tissue sample (biopsy) or remove the tumour.

The surgery can be performed in two ways, either:

- the surgeon makes some small cuts in your chest and inserts a small camera and surgical instrument called a thoracoscope; or
- the surgeon opens the chest cavity through a larger cut on your back.

Post-surgery, you will probably stay in hospital for a few days while you recover.

Mutation testing

Within each type of lung cancer there are subtypes. Several lung cancer subtypes can be classified by changes or mutations to specific genes.

By testing for these gene mutations your doctor can tailor your treatment regime for the best outcome. For example, from clinical trials, we know that NSCLC patients with certain mutations can significantly benefit from targeted therapies while patients without these mutations gain more benefit from standard chemotherapy.

For your cancer to be mutation tested, your doctor will require a tissue biopsy sample.

Further tests

You may have other tests such as blood and breathing tests, and bone, brain or MRI scans. If your medical team recommends surgery to treat your cancer, you may need to undergo further tests to ensure your heart and lungs can cope with the operation being considered. If you have any questions, please speak with your doctors or nurse.

Staging lung cancer

Based on the diagnostic test results, your doctor will assign the cancer a stage, between one and four. Staging the cancer helps your health care team determine the best treatment.

Staging is based on how much cancer is in the body and where it is located. It takes into account:

- the size of the cancer in the lung;
- whether it's present in other organs in the chest; and
- if it has spread to lymph nodes (glands) or to other parts of the body.

The most common tests to stage lung cancer include x-rays, CT scans, PET scans, bone scans, MRI scans, and sometimes more biopsies to test for cancer cells. Your doctor will work out the most appropriate combination of tests for you.

Small cell and non-small cell lung cancer stages

Stage 1	Only one lobe of the lung is affected.
Stage 2	The lung 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 and become attached to structures in the mediastinum 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.

3. Diagnosing Lung Cancer

Prognosis

A prognosis is the expected outcome of a disease. This is a general prediction because it isn't possible for any doctor to predict the exact course of your illness. Instead, your doctor can only give you an idea about the general prognosis for people with your type and stage of cancer.

Most people want to know how long they have to live. When asking this question, it's important to remember that your doctor doesn't have a crystal ball. They can't predict your future; they can only give an educated guess about your survival.

Sometimes, doctors have access to information on the average survival of a group of patients with the same type and stage of cancer like yours. When describing this information, the term you will hear used is 'median survival' period. This is the period at which 50 per cent (or half) of the patients remained alive after treatment finished.

The median survival period is not a fixed survival timeframe. It's a point in a timeline. For example, in a group of 200 patients two years post treatment, 100 people are alive – this is the median point. After five years, 50 people are alive and after 10 years, four remain alive. There are always people who are the exception to the rule and live much longer than the median, which is why your doctor cannot give you an exact answer about your expected survival.

Important factors in assessing your prognosis include 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.

The results of lung cancer treatments are best when the cancer is found and treated early, as with most types of cancer. People who have surgery in the early stages of lung cancer have the best chance of a cure.



Chapter Summary

- ▷ Clinicians use a range of tests to confirm a lung cancer diagnosis and help develop a treatment plan.
- ▷ Painless, diagnostic imaging tests – x-rays, CT scans or PET scans – are used to take pictures inside your body to see if you have a growth and if it has spread.
- ▷ To diagnose the type of cancer you have, a sample is needed for a pathologist to examine and test.
 - If you're coughing up phlegm, your doctor may ask you to collect some phlegm.
 - A sample of tissue may be collected from a growth via a biopsy. A 'core biopsy' is the most common procedure, where a small needle is inserted through the skin to take a sample from the growth.
 - A bronchoscopy is when a flexible tube is inserted through your nose or mouth and down into your lungs to examine your airways. During this procedure, the doctor may take a tissue sample. An endobronchial ultrasound is a type of bronchoscopy procedure.
 - Other methods for collecting tissue samples include a mediastinoscopy (to examine and sample the lymph nodes at the centre of your chest) and a thoracotomy.
- ▷ If enough tissue is available, your cancer may be tested for genetic mutations. This further diagnosis can help tailor your treatment.
- ▷ Based on the test results, your doctor will assign the cancer a stage, between one and four. Staging is based on how much cancer is in the body and where it is located – it defines how advanced the cancer is.
- ▷ When the tests are completed, your doctor will discuss with you a general predication, or prognosis, for the expected outcome of your disease. This is an educated guess about your survival based on the type of cancer you have and the rate and depth of tumour growth.



4. Multidisciplinary Care

You will be cared for by a range of health professionals, known as a multidisciplinary team, each of whom specialises in a different aspect of your treatment. Working with you, the team will develop a treatment plan to ensure you're provided with the best care. You may have different types of doctors on your multidisciplinary care team, depending on the stage of your cancer and your treatment option.

Your multidisciplinary team is likely to include:

- **a respiratory physician** – a doctor who specialises in diseases of the lungs and respiratory tract, they will help diagnose and stage cancer and determine initial treatment options;
- **a cardiothoracic (chest) surgeon** – does some diagnostic tests and performs surgery;
- **a pathologist** – examines samples of body tissue or fluids under the microscope to assist with diagnosis and staging lung cancer;
- **a medical oncologist** – a doctor who specialises in cancer treatment, they're responsible for devising your chemotherapy regime and subsequent treatment options such as targeted therapies;
- **a radiation oncologist** – a doctor who prescribes and coordinates the course of radiotherapy treatment and advises about side effects;
- **a radiologist** – specialises in using medical imaging techniques to see inside the body, e.g. CT scans;
- **a nuclear medicine physician** – A specialist who interprets your PET scan results (see page 10 for PET scans)



- **nurses and cancer nurse coordinators** – provide nursing care, information, coordination, support and assistance throughout your treatment; and
- **palliative care doctors and nurses** – who work closely with your GP and oncologist to provide supportive and palliative care for symptom management both in the home and hospital.

You, as the patient also form an important part of the multidisciplinary team. In addition, you may have access to other health professionals and an allied health multidisciplinary team. This may include:

- **a dietitian** – performs a dietary assessment and recommends an eating plan to follow during treatment and recovery;
- **a physiotherapist** – helps treat physical problems and address mobility issues caused by lung cancer, surgery and treatment side effects;
- **an occupational therapist** – helps you with everyday tasks like dressing, washing or cooking;
- **a speech pathologist** – helps with communication and swallowing issues if these arise;

- **a psychologist** – helps you work through fears and worries, resolve problems and teaches strategies to handle anxiety and depression;
- **a social worker** – provides support and information about emotional and practical issues such as financial issues, home help and childcare;
- **pastoral care** – most hospitals also provide patients with the opportunity to access pastoral care; and
- **other** – if you're a smoker, you will have access to resources to help quit.

Why it is necessary

A multidisciplinary team is needed to select the appropriate treatment plan for you because the planning process is complex and spans several medical disciplines. For instance, there are many options for treating lung cancer including drugs, radiotherapy and surgery, and most people with lung cancer receive more than one type of treatment. The order in which treatments are given is also important.

Your multidisciplinary team meets regularly, generally once a week, to discuss your individual case and the most appropriate treatment plan for you.

Benefits

From the start, it's important to get the prognosis and treatment correct. This means making an accurate diagnosis and identifying the correct stage of the lung cancer.



Working out the stage involves input from several different specialists (for example, pathologist, surgeon, medical oncologist, radiation oncologist). Research has shown that when you have the right pathology, the right diagnosis and the right stage, the outcomes are better. In addition, when a range of treatments is used, survival rates are better.

Choosing a team that suits you

At any time, you have the option to request a different treating doctor(s) or allied health provider. It's crucial that you trust and can talk with all the members of your medical team.

Chapter Summary

- ▷ Accurately diagnosing lung cancer and selecting the best treatment plan is complex and requires a team of health professionals working together. They're known as your multidisciplinary team.
- ▷ Depending on your treatment centre, you may also have access to an allied health multidisciplinary team.
- ▷ Your multidisciplinary team will meet regularly to discuss your case and treatment plan.
- ▷ You always have the option to request changes to your multidisciplinary or allied health teams.



5. Managing Lung Cancer Symptoms

Lung cancer can affect the surrounding lung tissue, causing symptoms such as coughing, bloodstained phlegm, breathlessness and chest pain. The cancer can also release substances that reduce appetite and cause weight loss with tiredness and, in some cases, insomnia. If the cancer has spread to other parts of the body, it can cause further problems such as abnormal lumps and pain. In general, the best way to improve lung cancer-related symptoms is to give treatment designed to treat or shrink the cancer.

Speak to your doctor or nurse about any symptoms you may be experiencing. In addition to cancer treatments, your doctor also may be able to help treat the cancer symptoms.

Managing pain

There is a range of prescription medications and alternative therapies available to manage the pain associated with lung cancer. Treatment depends on the cause of the pain, but relief is still available even if the cause of the pain is unknown.

Treatments include the different methods used to treat cancer such as surgery or chemotherapy; medications and other medical treatments specifically for pain; and a range of non-medication methods e.g. physiotherapy.

Many people find a combination of treatments helps, but everyone is different, so it might take time to find the right pain relief for you. If you're having treatment in hospital – e.g. chemotherapy or radiotherapy – it can take a few weeks for you to feel the effects, so you will usually be given a form of pain medication as well.

Sometimes it is not possible to completely control all pain. You may still feel some discomfort. However, your health professionals can help make you feel as comfortable as possible.

Managing sleep issues

Fatigue (lack of energy)

Fatigue includes feeling exhausted, tired, sleepy, drowsy, confused or impatient. Fatigue can appear suddenly and may not be relieved by rest. Some suggestions on how to manage fatigue are listed below:

- Let people help you. Family, friends and neighbours may offer practical help with tasks such as shopping, childcare, housework and driving.
- Take a few weeks off work during and/or after having treatment, or work fewer hours. You may be able to work at home.
- Do light exercise, such as walking, and keep up your normal exercise routine if approved by your doctor. Don't start any new exercise regimens until you have fully recovered from treatment.
- Try to eat a healthy, well balanced diet and don't skip meals. If you have nausea, be flexible about your meals.

Insomnia (sleeping difficulties)

Some lung cancer patients experience sleeping difficulties which result in a poor or unsatisfactory sleep. You may experience this as difficulty falling asleep, repeated or lengthy awakenings, inadequate total sleep time, or poor quality of sleep that can affect your normal daytime functioning.

Some suggestions on how to manage insomnia are:

- unless very unwell, maintain a regular wake up time;

5. Managing Lung Cancer Symptoms

- maintain a regular time to go to bed;
- get adequate exposure to bright light during the day;
- create a quiet, dark and restful environment for sleeping;
- be careful with caffeine – caffeinated drinks like tea, coffee and soft drink may boost your energy and mental alertness but make you feel jittery, irritable, anxious and can cause insomnia;
- if you're not sleeping well, tell your health care team – don't take any pills or medication unless they are prescribed as they may react badly with your treatment.

Managing nausea and loss of weight

Nausea and loss of weight can be a symptom of lung cancer. Even if you do not feel sick (nauseous) you may not feel hungry or enjoy foods that you used to like. Some tips on managing nausea and loss of appetite can be found on page 34.

If you are underweight or losing weight you will need to include more protein and more energy in your diet. This may involve eating foods that are high in fat and sugar. Including extra fat and sugar in your diet will be for a relatively short period of time.

Good sources of protein and energy include: meat, fish, poultry, milk and dairy products, eggs, legumes (e.g. baked beans, kidney beans, chick peas, lentils) and nuts. For extra protein: aim to include meat, fish or poultry at least once a day, and preferably more.

It is important to speak to your doctor, nurse or dietitian if you experience unwanted weight loss as they will be able to provide advice on a suitable eating plan for you.

Managing breathing difficulties

Managing breathlessness associated with lung cancer will depend on the cause of your breathlessness. There are several options to help alleviate your discomfort. Initially, your doctor may do some tests to measure your breathing, including measuring how much oxygen is making it into your bloodstream.

Medication

Your doctor may prescribe medication to help with breathlessness associated with lung cancer. These may treat pneumonia, wheezing, fluid build-up in the lungs or anxiety.

Breathing exercises

There are also relaxation exercises you can do to help manage breathlessness. A member of your medical team will teach you and your family exercises and techniques to do, so that you can practice them at home. They may also provide you with a take-home pamphlet outlining the exercises and techniques so that you can refer back to the exercise instructions if you find yourself in a difficult or stressful situation.

Managing cough

Cough is a common symptom of lung cancer which can be distressing if persistent.

Usually the best way to treat cough is to treat the lung cancer. If it is not possible to remove the cancer with an operation then using chemotherapy or radiotherapy to try and shrink the cancer can help to reduce cough. If the cough is associated with coughing up blood then sometimes a bronchoscopy will be recommended to locate the source of the bleeding and see if a local treatment such as laser can help you.



5. Managing Lung Cancer Symptoms

Medications in the codeine and morphine family can also be very helpful to reduce cough. They may be given as slow release tablets for 24 hour coverage or in a short-acting liquid form to take as a 'top-up' at times of sudden troublesome cough. Sometimes steam inhalations or saline given as a fine spray through a nebuliser are also helpful.

If you are coughing up green or dark yellow phlegm (sputum), you may have an infection and need to see your doctor about antibiotics. Your doctor can also assess to see if other non-cancer issues such as asthma, reflux, heart failure or certain medications could be contributing to your cough.

Other

Your doctor may recommend further treatment options to alleviate your breathing difficulties. These could include:

- chemotherapy or radiation to shrink a tumour (see Chapter 6);
- thoracentesis – if your shortness of breath is caused by a build-up of fluid in the lung lining (see Chapter 6); and
- oxygen therapy (in hospital and/or at home).

Chapter Summary

- ▷ You can experience a range of symptoms caused by lung cancer, from pain and breathing difficulties to weight loss and sleeping issues.
- ▷ Your specialist can prescribe medication to treat pain associated with lung cancer.
- ▷ Help manage your fatigue with the help of family and friends as well as through exercise and diet.
- ▷ If you are underweight or losing weight you will need to include more protein and energy in your diet. Your doctor, nurse or dietician can provide advice on a suitable eating plan for you.
- ▷ Manage insomnia through changes to your diet, environment and routine as well as medication.
- ▷ Your doctor will look to help you with any breathing difficulties through medication and/or breathing exercises.
- ▷ Your doctor can recommend a number of treatment options for cough. See your doctor if you are coughing up dark yellow or green phlegm as this may indicate infection requiring antibiotics.

6. Treatment Options

The treatment you receive will depend on your lung cancer type, for example, whether you have a non-small cell lung cancer Adenocarcinoma or Squamous cell carcinoma, and if this is a sub-type with a mutation. For the pathologist to make an accurate diagnosis, they will need an adequate tissue sample – either from an initial or subsequent biopsy.

Your multidisciplinary team will also take into account the stage of your lung cancer, your general health and breathing capacity, and your personal wishes.

While your health care professionals will do everything they can to cure your lung cancer, factors such as the stage of the cancer at diagnosis sometimes mean that their best efforts cannot achieve a cure. For some people with advanced lung cancer, treatment can keep the disease under control for months or years without curing it. Treatment also can help control symptoms such as pain to make life more comfortable.

Broadly speaking, the treatment options for the two types of lung cancer are:

- **Non-small cell lung cancer** may be treated by surgery, radiotherapy, chemotherapy or a combination of these.
- **Small cell lung cancer** is usually treated with chemotherapy. In some cases, chemotherapy may be given in combination with radiotherapy. Surgery is rarely used to treat this type of cancer.

Surgery

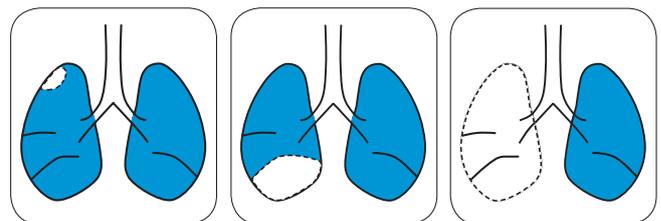
The surgical removal of a tumour offers the best chance of a cure for patients with early-stage cancer. To decide if surgery is an option, your multidisciplinary team will look at whether or not the cancer has spread beyond the lungs, as well as your general well being and fitness, and your breathing capacity, to see if you're fit enough for 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.

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.

Illustration source: Cancer Council NSW



6. Treatment Options

Thoracentesis (pleural tap)

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

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

Pleurodesis/tunnelled catheters

After having thoracentesis, fluid may re-accumulate between your lungs and chest wall. Your surgeon may perform another thoracentesis, but if the fluid continues to build up, your doctor may recommend a 'pleurodesis'.

During a pleurodesis, a surgeon will inject talcum powder between the layers of your lung tissue (pleura). The powder inflames the membranes and makes them stick together. This closes the space between the pleura and prevents the fluid from coming back.

For this procedure, you will be given a general anaesthetic and are likely to stay in hospital for about three days.

If the fluid continues to come back, your doctor may suggest you have a tunnelled catheter inserted into the pleural space. This can be an effective way to drain the fluid and can be managed at home by a community nurse.

Radiotherapy

Radiotherapy treats cancer using ionising radiation (usually x-rays) to kill cancer cells. It can be effective in treating lung cancer that has not spread outside the chest – particularly with tumours lying close to vital organs that can't be removed by surgery.

Radiotherapy is also used to treat cancer that has spread to the lymph nodes. In some cases, it may destroy all the cancer cells.

Radiotherapy options include:

- in combination with chemotherapy to treat lung cancer;
- after surgery to reduce the chances of the cancer coming back and to treat cancer that has spread;
- before surgery to shrink a tumour; and
- as palliative treatment to reduce symptoms, improve your quality of life or extend the length of life.

When planning radiotherapy treatment, your doctor will have a CT or PET scan taken of the treatment area. To ensure the same area is treated each time, the radiation therapist makes a few small permanent dot tattoos on your skin.

During treatment, you will lie on a treatment table. A machine that delivers the radiation will be positioned around you. The treatment itself will take 10 to 15 minutes. Receiving radiotherapy is painless and you should feel comfortable during the treatment.

Chemotherapy

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

Sometimes, chemotherapy is combined with surgery or radiotherapy. Commonly, oncologists recommend treating patients with chemotherapy when the cancer is large or has spread outside the lungs. Chemotherapy may be given for several reasons.

- Before surgery, to try and shrink the cancer to make the operation easier.
- During radiotherapy, to increase the effectiveness of the radiotherapy.
- After surgery – to reduce the chances of the cancer coming back.
- As palliative treatment, to reduce or help manage symptoms of your cancer, such as pain or coughing. Chemotherapy may help relieve these symptoms by shrinking a tumour. It has been shown that chemotherapy can help improve or maintain your quality of life and/or extend your length of life.

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

Chemotherapy is given in cycles that typically last for three to four weeks. Intravenous chemotherapy may be given for a few days and the rest of the cycle is a break from treatment. The number of treatment cycles you have depends on what type of lung cancer you have and how well your body handles the side effects. You will most likely receive treatment as an outpatient.

Maintenance therapy

Once you have completed the first-line treatment course, if your disease responded to the drugs your doctor may recommend ongoing 'maintenance' treatment with chemotherapy or another therapy. Although the concept of maintenance therapy is not new, its use is growing. One reason for this is that new cancer drugs have fewer side effects and patients may be able to take them longer.

In clinical trials of maintenance therapy, clinical researchers found that certain people with advanced lung cancer could benefit from the continuation of some treatments. The therapy can contain the spread of the cancer and help patients live longer.

Maintenance therapy can be split into two categories – continuation maintenance and switch maintenance.

- **Continuation maintenance:** after completing a defined number of cycles of combination therapy (more than one type of chemotherapy or other drug), your treatment is continued with just one of the agents. The single agent may be a targeted therapy or a chemotherapy agent.
- **Switch maintenance** entails switching to a third new drug (chemotherapy or targeted therapy) that was not included in your initial treatment regime. Switch maintenance may commence after the initial cycle of chemotherapy. The switch to the new therapy continues until the disease progresses.



Targeted therapies

Rapid technological advances have enabled the development of targeted therapies, also called biological therapies. This new frontier of research gives physicians the ability to tailor cancer treatment for more effective and potentially less harmful outcomes.

These therapies target specific biological differences between cancer cells and normal cells to allow the selective destruction of the proliferating abnormal cells without damaging healthy cells. Many targeted therapies are used in combination with chemotherapy.

How targeted therapies work

Each type of targeted therapy has a specific mechanism of action that interferes with cancer cell growth and reproduction during the development, growth and spread of cancer cells. Targeted therapies affect the ability of cancer cells to grow, multiply, repair and/or communicate with other cells but have few effects on normal cells, which reduces treatment side effects.

These therapies can act against one or more specific molecular targets, such as a protein, receptor, enzyme, or the formation of new blood vessels requested for the growth of the tumour. Others are based on the genetic make-up displayed by the cancer cells. Many of these therapies focus on proteins that are involved in the cell signalling process. By blocking the signals that tell cancer cells how to continuously grow and divide, targeted therapies can stop their growth and division.

6. Treatment Options

Depending on the subtype of your lung cancer, a targeted therapy may provide the best treatment option. This type of treatment may be recommended by your multidisciplinary team after your pathology and imaging tests have been analysed.

How targeted therapies are used?

Targeted therapies can be used alone, in combination with other targeted therapies, or in combination with other cancer treatments such as chemotherapy or radiotherapy.

Most of these therapies are available as pills and can be administered orally. This is a convenient way to receive cancer treatment with less impact on your quality of life. Other agents are given by intravenous infusion. The way the targeted therapy is given depends on the type of drug and its mechanism of action.

Many targeted therapies are still in the preclinical (laboratory) testing stage, some are available within clinical trials (testing in humans), and others have been approved for clinical use.

Case Study: Coleen's treatment

In 2006, a 57-year-old Victorian midwife, Coleen, found an unusual lump on her neck. Tests lead to a diagnosis with advanced, inoperable stage 3B non-small cell lung cancer. However, Coleen had to wait four weeks before starting treatment.

"The wait seemed like forever but my medical oncologist and radiation oncologist wanted the treatments to run concurrently and everything had to be absolutely spot on before they started," said Coleen.

Coleen had an initial treatment of five weeks of radiotherapy plus chemotherapy. This was followed by a second line of chemo which was completed in early 2007.

The tumours shrank and although x-ray and scan results always mention radiation damage they also have the magic words, "No Evidence of Disease".

Coleen praised her multidisciplinary team.

"At my first appointment, my radiation oncologist inspired me with his comment 'we can cure this'," she said.

"My medical oncologist also has been wonderful, professional and knowledgeable, but displaying the utmost caring and compassion...I trust him with my life, literally.

"I must also mention the chemo and radiation nurses – they're truly special and I'll be forever thankful for their gentleness, hugs and humour."



Chapter Summary

- ▷ There is a range of lung cancer treatments available. Your treatment will depend on your type of cancer and its stage, your general health and breathing capacity, and your personal wishes.
- ▷ There are four types of treatment, which may be used individually or in combination.
 - Surgery to remove a tumour offers the best chance of a cure for patients with early-stage cancer.
 - Radiation treats cancer by killing cancer cells, it can be effective in treating lung cancer that hasn't spread outside the chest.
 - Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. It may be used in combination with surgery, radiation or targeted therapies.
 - Targeted therapies are a new type of medication that acts against one or more specific molecular targets characterising a subtype of lung cancer.



7. Lung Surgery: Preparation and Recovery

Preparing for surgery

How you recover from lung surgery will depend on many factors. However, you can control two factors.

If possible, **increase your fitness** and physical activity level prior to surgery to help with your recovery. Walking is a great exercise (not power walking, just moving regularly). Any walking will benefit your overall recovery from surgery. Prior to surgery, aim to walk at least 20 to 30 minutes, once or twice a day. Begin by walking short distances often, and then slowly increase the distance.

If you're a smoker, it is critical that you **stop smoking**. Smoking drastically increases the risk of post-operative complications after lung surgery. This means it's beneficial to stop smoking before surgery. Speak to your GP for advice and support on quitting smoking (also see Chapter 11).

Planning a hospital stay

When planning for your hospital stay, consider the following.

- How you will get to hospital and home from hospital?
- Arrange to have someone at home with you for at least two or three days after you leave hospital.
- Organise help with chores at home such as your shopping, laundry, housework, pets and mowing.
- Look into any changes that need to be made to your financial arrangements.
- Request medical certificates from your doctor, if required.

Allied health professionals

Allied health professionals are available to assist with problems that may interfere with your hospitalisation and recovery progress. These professionals may be drawn from various health departments including social work, occupational therapy, dietary and pharmacy. If you're concerned about how you will cope at home after the surgery, notify your case manager before your admission and a consultation will be arranged with the appropriate allied health worker.

Anaesthetic

Before going to surgery, you will have an anaesthetic assessment in preparation for your general anaesthetic. You will be given an injection before going to the operating room. If you have had problems with an anaesthetic previously, let the anaesthetist know. The injection will make you feel relaxed, drowsy and dry in the mouth before you go to sleep.

Blood transfusion

Blood transfusions are seldom needed during lung surgery, but if unexpected bleeding occurs, you may need a transfusion. During your pre-admission process, a blood sample is taken so donor blood can be matched with your blood. This is so that in the event of bleeding, blood can be obtained quickly.

Bowels

No special bowel preparation is necessary prior to lung surgery. However, if you normally have bowel problems, discuss with your doctor any medication or treatments you use for this, including prescription medications, over-the-counter or herbal remedies.

7. Lung Surgery: Preparation and Recovery

Diabetes

If you have diabetes, make sure you tell your surgeon prior to admission and tell the staff on admission. Special arrangements will be made as necessary. Your blood sugar levels will be monitored closely from the time you start fasting (prior to surgery) until normal eating resumes. It's important that you don't take diabetic medication on the morning of your surgery.

Fasting, fluids and food

You must fast from midnight the night before your surgery. That means no food or fluids after midnight. This is called 'Nil by Mouth' or NBM. The only exception to this is that you can take morning tablets with a sip of water at 6am.

The evening after your surgery, you can have ice and sips of water only. If you have a complete lung removed, your fluids will be restricted after surgery.

Medications

Bring with you a list of the names, dose and time of day that each of your medications is taken. This enables the accurate and timely ordering of the medications you will take while in hospital.

You must continue to take your medication up to the time of admission, except if your surgeon requests you to stop any particular medications. For example, if you're taking blood-thinning tablets such as Aspirin, Warfarin/Coudamin or Plavix/Clopidigrel your doctor will ask you to stop taking these prior to surgery.

Skin preparation

You should shower the evening before and the morning of surgery.

For men, your chest area will be shaved or clipped once you're admitted. It's recommended that you don't attempt to shave the area yourself before going to hospital.

Physiotherapy

Your recovery process from lung surgery is dependent on effective physiotherapy.

Physiotherapy maximises the functioning of your lungs by:

- helping you remove secretions from within your lung;



- improving distribution of air throughout the lungs;
- preventing collapse of the lung; and
- preventing pneumonia or chest infection.

You should begin physiotherapy at home during the days before going to hospital. Your physiotherapist may recommend the following breathing exercises both before and after surgery.

Active cycle of breathing technique

This technique involves using certain breathing manoeuvres in the following sequence to improve airflow and remove secretions.

- 1) Take three deep breaths (hold each one for three seconds)
- 2) Return to normal breathing
- 3) Huff twice
- 4) Strong cough

Breathing manoeuvres

Deep breathing: Breathe in as deeply as possible, directing the air into the bottom of your lungs. Hold your breath for two to three seconds then breathe out slowly. Repeat three to five times.

Huffing: Take a medium-sized breath in. Then, with a half opened mouth, force the air out while making a soft 'haa' sound (similar to the sound you make when huffing on spectacles to clean them).



7. Lung Surgery: Preparation and Recovery



Supported cough (post surgery): Place your hand or a towel over your incision and secure it with your elbow. Take a deep breath, and then cough. One good strong cough per cycle is more effective than repeated little ones.

Note: If you feel dizzy while doing any of these exercises, stop immediately. You may be taking too many deep breaths, one after the other. After you have rested, try again with fewer repetitions. Before, and to prepare for, your surgery, practice these exercises at home. Take note of how it feels to take a maximal deep breath.

Walking

Walking is important to maintain your overall fitness prior to surgery. Walking daily improves your fitness levels, clears your lungs, and facilitates a speedy recovery after surgery.

Recovering from surgery

Your multidisciplinary team will devise a program to help you return to your pre-surgery level of activity. A speedy recovery after lung surgery requires work.

Initially, your mobility will be limited because of the chest tubes attached to a suction unit. However, exercising continues at the bedside and your activity will be increased according to what you can tolerate.

Your aim is to be independently mobile when you leave hospital, though you may be slower than usual and tire more quickly. This will include being able to shower, dress and feed yourself and do your deep breathing and coughing exercises.

Regaining your strength is best done at home in combination with healthy food, good company for support, and quietness for rest.

Immediately after the operation

You will wake up from the anaesthetic with an oxygen mask over your face. You will be observed closely in the recovery room of the operating theatres. When sufficiently awake and comfortable, you will return to the ward or intensive care unit. The nursing staff will wash you, make you comfortable and observe you closely. Observations will involve monitoring your blood pressure, temperature, pulse, blood oxygen level, chest drain tubes, wound and pain levels.

Anti-blood clotting methods

Blood clots forming in the legs and lung are a risk factor with any surgery. To help prevent clots, you will be given an injection.

If you're required to wear compression stockings while in hospital, it's a good idea to continue wearing them for several weeks at home. For them to be effective, you will need to ensure they are worn properly, that is, pulled up to the knees.

Exercise has been proven to reduce the risk of blood clots after surgery.

Chest tubes/drains

When you wake from surgery, you will have one or two tubes in your chest wall. These tubes are necessary to:

- assist the lung that has been operated on to re-expand;
- enable fluid related to the operation to be drained from the chest cavity; and
- to allow air that has leaked from the operation site to escape.

The tube will cause some initial pain. The time it remains in place varies from patient-to-patient. Chest x-rays are performed regularly while the tube(s) is in place and an x-ray will be taken after the tube(s) is removed.

After your chest drain has been removed and your wound has closed and healed (that is, it no longer requires dressings), you can start massaging your scar. Massage keeps the scar tissue mobile and helps with your shoulder movement.

“ I had my surgery on the 20th October 2011. The surgeons removed my right lung and all the tumours in and around my chest. My recovery was good. I was up and walking the next day – no tubes or oxygen, just me and the physiotherapists. ”

Sandy (diagnosed July 2011)

Initially, the scar may be uncomfortable to touch and may feel more sensitive than normal. However, the more you touch it, the less sensitive and more comfortable it will become.

You can use Vitamin E cream, sorbolene or lanolin oil to massage the scar. Using your fingertips massage in a circular motion, so the scar and skin move over your ribcage. Begin gently, then as you get used to it, press more firmly. Generally, the tip of your fingernail should turn white while massaging your scar.

Nausea and vomiting

Some patients experience nausea and or vomiting after surgery. These symptoms may be related to the anaesthetic or pain relief medication. Nausea and vomiting can be treated with medication so please tell the nursing staff if you experience these symptoms. Also, tell the anaesthetist and staff about any prior experiences you have had with nausea and/or vomiting following anaesthesia.

Oxygen therapy

All patients require oxygen via a mask immediately after surgery. The mask is usually replaced with nasal prongs – a fine tube that sits inside the nose. The oxygen will dry your mouth and lips, so apply lip cream while on oxygen therapy.

The need for oxygen varies between patients. Most patients are weaned off oxygen therapy before returning home, however, when required home oxygen can be arranged.

Physiotherapy

A physiotherapist will visit you soon after you return to the ward and prescribe a specific exercise program.

Physiotherapy is the most important aspect of your post-operative recovery. After your drains have been removed, you will be expected to move, walk, or be active every hour during waking time. Pain relief will help you to do the necessary exercises.

To maximise your recovery, you should continue the exercises you learn in hospital after you return home.

Maintaining your posture

After the operation, you may be tempted to 'favour' or lean towards your operated side. This can lead to unnecessary discomfort due to muscle spasm from holding an abnormal position. You will be assessed, advised and assisted to maintain your posture. If you're not sure, look in a mirror or ask a friend/relative if you appear to favour one side.

Getting out of bed and early walking

Walking soon after surgery is an effective way to prevent complications of the chest. Walking causes you to take deeper breaths and expand the bases of your lungs. This leads to stronger and more effective coughs that help to remove secretions from your lungs and to prevent infections.

The day after surgery, you will be asked to sit out of bed. The physiotherapist will help you to start 'marching on the spot'. When the chest drain is detached from suction, and you become less restricted by the chest tube(s), you will start walking down the corridor.

7. Lung Surgery: Preparation and Recovery

Getting ready for home and after discharge

When the physiotherapist advises you that you're ready to walk on your own, your self-directed walking program will begin. This involves walking in the ward five to six times throughout the day.

By the time, you leave hospital you will be independent, able to walk up a flight of stairs (if you could do this before admission) and increasing your physical activity daily.

At home, you will be expected to walk regularly – aiming to return to at least your pre-operation level of activity within four to six weeks. Continuing with a frequent walking program will help to improve your lung fitness and assist with secretion clearance. Walking and exercise also stimulates bowel activity, appetite and an overall feeling of mental and physical well-being.



Arm exercises post-thoractomy

After a thoracotomy, your rib cage may feel stiff or tight on the side of the operation. A physiotherapist will assist you to do simple arm exercises to help relieve the tightness. You should keep doing these exercises until you no longer feel tightness.

You may be given the following exercises. Do these exercises every morning and night, three times each, and hold each movement for 10 seconds. Within four to six weeks, your shoulder movement should be similar to how it was before surgery.

Shoulder flexion: Lift your arm forward and raise it towards the ceiling. Hold for 10 seconds, and then lower slowly. (If it's too sore to lift straight up, walk your fingers up a wall. Hold for 10 seconds when you feel a stretch (not pain) and repeat three times. As soon as you can, progress to lifting your arm straight up to the ceiling.)

Shoulder abduction: Lift your whole arm sideways, away from your body. Hold for 10 seconds, and then lower gently. (If it's too sore to lift straight out, walk your fingers up a wall, hold for 10 seconds when you feel a stretch (not pain) and repeat three times. As soon as you can, progress to lifting outwards.)

Side flexion: With both arms relaxed by your side, gradually lean sideways and slide one arm down your leg. Lean away from the operation side to feel a stretch on that side. Hold for 10 seconds and repeat three times.

Postural stretch: Sit firmly on a chair, holding a stick (or towel) with a wide grip. Lift the stick up with your arms straight and extend your upper trunk at the same time. If you have restricted movement in your shoulder, simply move within your pain-free range.

Chapter Summary

Preparing for surgery

- ▷ Improve the speediness of your recovery by walking daily and, if you're a smoker, speak to your GP about quitting smoking.
- ▷ A physiotherapist will provide you with breathing exercises to begin before surgery to maximise your lung function.
- ▷ Plan for your hospital stay by arranging transport, post-hospital support at home and medical certificates; allied health professionals may be able to help you prepare for coping at home post-surgery.
- ▷ Before surgery, you will need to:
 - have an anaesthetic assessment and your blood type;
 - fast from midnight the night before your surgery; and
 - shower the evening before and the morning of surgery.

Recovering from surgery

- ▷ You will wake from surgery, wearing an oxygen mask and with one or more drainage tubes in your chest. You will be given an injection to prevent blood clots.
- ▷ Immediately after surgery, you may experience some nausea or vomiting – this can be treated.
- ▷ A physiotherapist will work with you to develop an exercise program to aid your recovery. They will oversee your exercise in hospital and devise a program for you when you return home.



8. Treatment Side Effects and Management

Different drugs and treatments have different side effects. When starting treatment, don't be afraid of the side effects. Your doctors and nurses will discuss them with you and help you to deal with them. Always tell your medical team about the side effects you experience so that they can support and manage them. In most cases, they can prescribe drugs to make the side effects less severe.

Most chemotherapy drugs can cause side effects, with the most common including nausea, fatigue, hair loss and skin rashes. Chemotherapy specific side-effects are addressed on page 38. The side effects will depend on what kinds of drugs you're given.

The side effects of radiotherapy include localised burning where the radiotherapy was applied, scarring and shortness of breath. Radiotherapy specific side effects are addressed on page 37. The side effects will depend on the part of the body being treated, and the radiation dosage.

With targeted therapies, you can experience side effects on the blood and immune system and skin as well as fatigue and diarrhoea. Targeted therapies specific side effects are addressed on page 39.

Duration of side effects

After treatment ends, most side effects will gradually disappear as the healthy cells quickly recover.

The time it takes to get over some side effects and regain energy varies from person-to-person. It depends on many factors, including the type of therapy you received and your overall health.

Patients often become discouraged about the length of treatments and side effects. This can make it difficult to continue treatment. If you have this feeling, talk to your doctor who will evaluate whether to adopt measures to counter the side effects and whether to change your medication or treatment schedule.

Side effects common to all treatments

Effects on the blood and immune system

Radiation as well as some chemotherapy and targeted therapy drugs can affect the bone marrow (the soft, spongy material inside the bones).

The bone marrow makes three types of blood cells:

- red blood cells that carry oxygen throughout the body and help prevent anaemia;
- white blood cells that fight infection; and
- platelets that helps blood clot and prevents bruising.

The bone marrow maintains normal levels of blood cells (your blood count) to keep you fit and healthy. When treatment affects the bone marrow, your blood count falls. The count may decline with each treatment. This can cause some problems, depending on the type of blood cells affected.

Anaemia

Having anaemia (being anaemic) can make you look pale, feel weak and tired, and possibly breathless. You may need a blood transfusion to build up your red blood cells and to treat the anaemia. You can also manage anaemia by eating a diet with adequate amounts of nutrients, including iron and B vitamins; and eating wholegrain breads and cereals, lean meat and green leafy vegetables.

Infections

White blood cell numbers may drop during treatment. This can make colds and the flu harder to shake off, and scratches and cuts may become infected easily or take longer to heal.

See your doctor if you're unwell and don't wait out a cold when you're having chemotherapy. Doctors sometimes recommend taking antibiotics as a precaution against infection. If you're having treatment – particularly chemotherapy – in winter, check with your doctor about having the flu and H1N1 (swine flu) vaccines.

Lung cancer treatment can temporarily weaken your immune system, so your body may have trouble fighting infections – if you have a high temperature (38°C or above) while receiving treatment, seek medical advice.

Managing infection

- Wash your hands with soap and water before preparing food, eating and after using the toilet.
- Keep a thermometer at home to check your temperature if you feel unwell. If your temperature is over 38°C call your treating team immediately as you have a fever (a healthy body temperature falls in the range of 36.5 to 37°C).
- Try to avoid sick people. Some people having chemotherapy prefer not to go to crowded places such as shopping centres, to minimise the risk. This is not always practical, so use common sense.
- Let your doctor know if you're in contact with a person who has chickenpox. You may need an injection to prevent chickenpox or shingles.

Bleeding problems

A fall in the number of platelets can cause you to bleed for longer than normal after minor cuts or scrapes, or to bruise more easily. You may need a platelet transfusion if they are low.

Managing bleeding problems

- Be careful not to cut or nick yourself when using scissors, needles, knives or razors. Small cuts can be a site for an infection to start.
- Clean your teeth with a soft toothbrush to avoid scratching your gums and making them bleed.
- Use an electric razor to minimise the chance of nicking yourself.
- When gardening, wear thick gloves to avoid injury and prevent infection from soil, which contains bacteria.
- If you bleed, apply pressure for about 10 minutes and bandage, if appropriate.

Your medical team will do regular blood tests to make sure your blood cells return to normal before your next treatment.

Fatigue

Fatigue includes feeling exhausted, tired, sleepy, drowsy, confused or impatient. Fatigue can appear suddenly and may not be relieved by rest. After a treatment cycle ends, you may continue feeling tired for weeks or months. Fatigue can be disabling as it can prevent you performing daily activities.

Symptoms of fatigue can include:

- feelings of powerlessness,
- irritability and sadness,
- drowsiness,
- reduced care in your appearance, and
- a decline in sexual desire.

Fatigue can last for a short time if it's related to the treatment. It may improve or disappear if your doctor reduces or discontinues the treatment.

During radiotherapy, your body uses a lot of energy dealing with the effects of radiation on normal cells. Your weakness and weariness may build up slowly during the course of treatment, but should go away gradually after treatment is over.



8. Treatment Side Effects and Management



Managing fatigue, tiredness and lack of energy

- Arrange activities across the whole day, rather than for just part of it.
- Try to eat a healthy, well balanced diet and don't skip meals. If you have nausea, be flexible about your meals.
- Drink 1.5 litres of liquid during the day.
- Let people help you. Family, friends and neighbours may offer practical help with tasks such as shopping, childcare, housework and driving.
- Take a few weeks off work during and/or after having treatment, or work fewer hours. You may be able to work at home.
- Do light exercise, such as walking, and keep up your normal exercise routine if approved by your doctor. Don't start any new exercise regimens until you have fully recovered from treatment.
- Do relaxation techniques and relax with music or read a book.
- Be careful with caffeine. Caffeinated drinks like tea, coffee and soft drink may boost your energy and mental alertness but caffeine can make you feel jittery, irritable, anxious and can cause insomnia.
- Try to get more sleep at night and if you can, take naps during the day.

- If you're not sleeping well, tell your health care team. Don't take any pills or medication unless they are prescribed as they may react badly with your chemotherapy treatment.

Loss of appetite, nausea or vomiting

It's common for your appetite to change while going through treatment. Sometimes you may not feel hungry, or you may not enjoy foods that you used to like.

Not everyone feels sick (nauseous). However, if you do experience nausea it may kick in a few hours after treatment begins and could last for many hours. Sometimes, nausea doesn't occur until several days after chemotherapy.

Nausea may be accompanied by vomiting or retching. If you have vomited a lot, try to keep your fluids up so that you don't get dehydrated. If you can't keep fluid down, call the hospital.

Anti-nausea medication can help. This medicine can be taken before, during or after chemotherapy treatment. It may be available as tablets or wafers (which dissolve under the tongue), in liquid form, or as a suppository (which is placed in the rectum where they dissolve). Check with your doctor or nurse whether it's safe to use this type of medication. You may be given anti-nausea tablets to take at home. Some tablets you take regularly after chemotherapy treatment to prevent nausea, others you can take any time you feel ill.

If the standard anti-nausea medications don't work for you, there are others available. Let your nurse or doctor know early on if your symptoms aren't being relieved. If you still feel nauseous after a few days, or are vomiting for more than 24 hours, contact your doctor as you may become dehydrated.

During radiotherapy, you may have an upset stomach, develop a metallic taste in the mouth, lose interest in food and there may be days when you don't feel like eating much.

Managing loss of appetite and nausea

- Eat a light meal before your treatment (e.g. soup and dry biscuits) and drink as much fluid as possible.
- After treatment, drink small amounts more often rather than large drinks. Try soda water, dry ginger ale or weak tea. Ice cubes, ice-blocks or jellies can help increase your fluid intake.

8. Treatment Side Effects and Management

- Avoid foods that usually upset your stomach.
- Eat small, frequent snacks instead of large meals. Try to eat when you're hungry. Not eating can make the nausea worse.
- Eat slowly and chew well to help you digest your food better.
- Eating dry toast or crackers often helps.
- You may find you can drink a lot, even if you don't feel like eating solid foods. If so, try enriching your drinks with powdered milk, yoghurt, eggs, and honey or weight-gain supplements.
- Take it easy after eating a meal.
- Try breathing deeply through your mouth if you feel like you're going to vomit.
- Prepare meals between treatments and freeze them to use on the days you don't feel like cooking.
- Try to catch up by eating extra on days when you have an appetite.
- Try to avoid odours that bother you or put you off eating, such as cooking smells, perfume or smoke.
- Ask your doctor for medication to stop you feeling sick.
- Talk to the hospital dietitian for advice about the best diet during treatment and recovery.

Managing vomiting

After vomiting, treat your empty, irritated stomach gently to help get it back to normal. You can do this in stages.

- **Stage 1 – Small Sips.** If you have persistent vomiting, don't try to force food down. Sip small amounts of liquid as often as possible, for example dry ginger ale, cold flat lemonade and soda water; suck a hard lolly, flavoured crushed ice-cubes or ice blocks.
- **Stage 2 – Introduce drinks slowly.** Once your vomiting has stopped you may still feel nauseated and full. Hunger can aggravate or prolong nausea so it's important to eat small, frequent meals.

Start by drinking cold or iced drinks. Make up drinks that are half milk (or skim milk) and half water (or soda water). These mixtures are surprisingly settling and soothing. Try a spoonful of ice cream in a glass of lemonade or diluted fruit drinks if you like sweet drinks. Jellies can be satisfying and gentle on the stomach too.

- **Stage 3 – Introduce solid foods.** When you feel you can drink without discomfort, eat small amounts of solid foods, such as plain dry biscuits, toast or bread with condiments. Try jelly or cooked rice or sago, and then try stewed fruit such as apples, pears or peaches. Start drinking milk products gradually and in small amounts. Yoghurt is an easily digested milk product. When eating, don't drink more than a few sips of liquid in order to leave enough space for food.
- **Stage 4 – Return to normal diet.** As soon as you can, increase your food intake until you're eating a normal well-balanced diet. Your doctor or dietitian may advise you to take additional supplements on your good days to make up for the days when you can't eat properly. Foods your sensitive stomach may not be able to tolerate include fatty or fried foods, creamy or rich foods, starch foods such as potatoes, and spicy or oily sauces. It's best to limit these where possible.

Constipation

Some chemotherapy drugs, pain relief medicines and anti-nausea drugs can cause constipation. If you have constipation for more than a couple of days, let your doctor or nurse know. Your medication may need to be changed or other medication given to relieve it.

Managing constipation

- Eat more high-fibre foods, such as wholegrain bread and pasta, bran, fruit and vegetables.
- Drinking fruit juice can help ease constipation. Try prune, apple or pear juice.
- Drink plenty of fluids, both warm and cold to help loosen the bowels.
- Exercise lightly.
- Eat small, frequent snacks instead of big meals.

8. Treatment Side Effects and Management



Diarrhoea

Diarrhoea may be caused by some chemotherapy drugs, targeted therapies, pain relief medicines, anti-nausea drugs and/or anxiety, or bacterial infection.

If you have diarrhoea, it's generally treated with medication at home. However, if the diarrhoea becomes severe, it may cause dehydration and you may need to be admitted to hospital. Tell your doctor or nurse before your next treatment session if you have had diarrhoea.

Since most targeted therapies are taken by mouth, diarrhoea may occur immediately after starting the treatment or after several days. Usually you return to normal a few days after the drug is stopped. In some cases, diarrhoea can interrupt the course of your targeted therapies and/or result in a smaller dose. Your doctor will assess the scale of this side effect and decide what measures to adopt.

Managing diarrhoea

- Eat smaller amounts of food and eat more often.
- Try snacking on clear broth and toast, biscuits or cooked rice.
- Consume food and drink at room temperature (neither hot nor cold).
- To replace fluids lost through diarrhoea drink six to eight glasses of non-carbonated drinks (water, apple juice, peach juice, apricot juice, clear broths, green tea, ginger ale, Gatorade, or similar).

- Eat foods rich in potassium, such as bananas, apricots, peaches or potatoes.
- Choose simple foods (rice, vegetable soups, fruits and vegetables without skin, fish, chicken and turkey, eggs and yoghurt).
- Avoid coffee (or drinks with caffeine), tea and alcoholic beverages.
- Avoid spicy, fried or greasy foods.
- Avoid rich gravies and sauces.
- Avoid milk and milk products.
- Avoid high-fibre foods, i.e. wholegrain products, broccoli, cabbage, cauliflower, beans, bread, cereals, bran, raw fruits and/or vegetables with skin.
- Avoid citrus (e.g. orange juice).
- Avoid chocolate.

Skin conditions

Even moderate cases of itchy or dry skin can be annoying. Drugs can relieve itching but it is important that you seek advice from your doctor.

Radiotherapy may make your skin dry and itchy in the treatment area, and may temporarily look red, tanned or sunburnt. If you're having radiotherapy, it is not advisable to use sunscreen so you must protect the treatment area from the sun. Stay out of the sun when possible and before going outdoors cover your treated skin with light, close-weave clothing.

When having chemotherapy, your skin may darken, peel or become dry and itchy. It also may be more sensitive to the sun. Therefore, it is particularly important for people having chemotherapy to protect their skin from the sun (especially between 10am and 3pm) by wearing high-protection sunscreen (SPF30+), a hat and protective clothing.

Dry skin and itchiness is also a common side effect with targeted therapies.

Managing skin conditions

For dry skin:

- Use a moisturising lotion that contains urea or sorbolene cream, to stop the dryness.
- Avoid hot baths and long showers.
- Use a neutral detergent and add oil to your bath.
- Use a colloidal oatmeal wash, rather than soap, to wash the affected area.
- Pat your skin dry with a soft towel.
- Use a baby shampoo. Avoid dandruff shampoos (they contain more chemicals).
- After your bath (and regularly during the day) apply a mild, alcohol-free moisturising cream. You might find it useful to use oatmeal, colloidal lotions, aloe, or glycerine.
- Avoid prolonged sun exposure. Always use a sunscreen of SPF15 or higher (preferably containing zinc oxide or titanium dioxide) on exposed areas of your body (face, neck and extremities), unless you're having radiotherapy.
- Wear loose, comfortable clothes. Wear soft fabrics like cotton next to your skin. Avoid rough fabrics.
- Protect your skin from cold and wind.
- Maintain good hydration by drinking at least 1.5 litres of liquid during the day.

For itchiness:

- Apply cold compresses (i.e. ice in a plastic bag wrapped in a towel).
- Keep nails short and well treated (to avoid scratches). Don't push the nail cuticles back or file the sides of the nails into the skin.
- Try to wipe or dab the skin rather than scratch.
- Change your bed sheets regularly. Don't have too many blankets on your bed.
- Menthol talc on your arms, legs, stomach and back may also give you relief.

Radiotherapy – managing side effects

Side effects from radiotherapy vary considerably. People having the same treatment may react differently while reactions can vary from one period of radiotherapy to the next. The type and severity of your side effects have nothing to do with the success of your treatment.

Before your treatment begins, talk to your radiation oncologist about possible side effects. These usually start around the second or third week of treatment and are at their worst two-thirds of the way through a course of treatment.

During treatment, tell your radiation oncologist, radiation therapist or nurse if you have any side effects. There are ways to reduce any discomfort you experience. For example, your doctor may prescribe medications to help you feel better. If you have a particularly severe side effect, your doctor may suggest a break in your treatment or a change in your treatment, but this is rare.

Some side effects of radiotherapy may occur weeks or months after treatment has finished. Always consider the possibility that any new symptoms you experience may be related to treatment and mention them to your doctor. Delayed but temporary radiation side effects can include:

- inflammation of the lung resulting in a cough and shortness of breath; and
- irritation of the spinal nerves causing electric shock like sensations in the legs.

Neck and chest problems

After about two weeks of treatment, your mouth or throat may become dry and sore, and your voice hoarse. You also may have some phlegm in your throat, or a lump-like feeling that makes it hard to swallow. This is due to a sunburn-like reaction in the gullet (food tube).

Managing neck and chest problems

- Suck ice chips and sip cool, refreshing drinks.
- Try to have more liquids if swallowing is painful.
- Avoid hot or acidic drinks.



8. Treatment Side Effects and Management

- If eating is uncomfortable or difficult, ask for something to relieve the pain. Good pain relief will help you eat well and feel better.
- If you have difficulty swallowing, speak to your treating team. They may recommend you see a speech pathologist or dietitian.
- You may need to tailor what you eat to ease the 'sun burning effect' on your swallowing tube. Try soups and smoothies for comfort and nutrition.

Radiotherapy side effects that are common to all treatments are addressed on pages 32 to 37.

Chemotherapy – managing side effects

Chemotherapy kills cancer cells. However, the treatment can also affect normal cells and this may cause side effects.

Side effects vary greatly. Some people will have no side effects and others will experience many. Reactions vary from person-to-person, according to the type of drugs used, and from one treatment period to the next. Side effects usually start during the first few weeks of treatment. Fortunately, most are temporary and can be managed.

The type and severity of any side effects is not a sign of the treatment's success. Before your treatment begins, it's best to talk to your doctor or nurse about the side effects you should watch out for or report. They can also tell you whom to contact out of hours if you have any immediate concerns.

It's important to tell your doctor if you plan to take any over-the-counter medications, home remedies or complementary therapies. Some of these medicines may worsen your side effects or affect how the chemotherapy works in your body. For example, the herb St John's Wort can reduce the effectiveness of some chemotherapy drugs.

Mouth sores

Some chemotherapy drugs can cause mouth sores such as ulcers or infections. If you notice any change in your mouth or throat, such as sores, ulcers or thickened saliva, or if you find it hard to swallow, contact your doctor.

Managing mouth sores

- Use a soft toothbrush to clean your teeth twice a day.
- Don't use commercial mouthwashes that contain alcohol. They may dry your mouth out or irritate it. Your doctor will give you a special mouthwash to prevent mouth infections.
- At least four times a day, rinse your mouth with a teaspoon of bicarbonate soda or salt in a glass of warm water. Bicarbonate mouthwash helps keep the mouth clean and salt mouthwash helps heal mouth sores.
- Sucking on ice while an infusion (drip) is being given can help minimise mouth ulcers.

When to contact your doctor

Contact your doctor urgently if any of the following occur:

- chills or sweats;
- a temperature higher than 38°C;
- persistent or severe vomiting more than 24 hours after treatment;
- severe abdominal pain, constipation or diarrhoea;
- unusual bleeding;
- tenderness, redness or swelling around an injection site; and
- any serious unexpected side effects or sudden deterioration in health.

Also contact your GP or treating specialist if you experience:

- sweating, especially at night;
- sore throat;
- mouth ulcers;
- burning or stinging on passing urine; and
- easy bruising.

8. Treatment Side Effects and Management

- Sip fluids, especially water, and eat moist foods such as casseroles if you have a dry mouth. Moisten foods with butter or sauces. It may help to suck on frozen pineapple or chew gum.
- Blend foods to make them easier to eat.
- Eat soups and ice creams.
- Avoid spicy or acidic foods as they can aggravate mouth sores.

Chemotherapy side effects that are common to all treatments are addressed on pages 32 to 37.

Hair loss and scalp problems

Many people having chemotherapy worry about losing their hair. Some people lose all their hair very quickly, others lose it after several treatments, and others may lose only a little or no hair at all. Hair loss can vary depending on the chemotherapy. Your treating team will advise you if hair loss will occur.

Hair loss usually starts two to three weeks after the first treatment and grows back when chemotherapy is completed. Your scalp may feel hot or itchy. In addition, it also may feel tender just before and when your hair starts to fall out. Although head hair is the most common form of hair loss, some people also may lose hair from their eyebrows, eyelashes, arms, legs, chest and pubic area.

It takes four to 12 months to grow back a full head of hair. When your hair first grows back, it may be a different colour or it may be curly (even if you have always had straight hair). In time, your hair will return to its normal condition.

Managing hair loss and scalp problems

- Keep your hair and scalp very clean.
- Use a mild shampoo like baby shampoo.
- Wear a light cotton turban or beanie to bed if you're cold at night.
- Use a cotton, polyester or satin pillowcase (nylon can irritate your scalp).
- Make an appointment with a hairdresser to make your hair look as good as possible, even if it's thin or patchy. Avoid perms and dyes, and limit the use of hair dryers, rollers and harsh products.

- If your eyelashes fall out, wear glasses or sunglasses to protect your eyes from the sun and dust while outside.
- Comb or brush your hair gently using a large comb or a hairbrush with soft bristles.
- If you prefer to leave your head bare, protect it against sunburn and the cold.
- If you plan to buy a wig, choose it early in your therapy so you can match the colour and style of your own hair.
- See Changing Body Image section on page 49, for more information.

Nerve and muscle effects

Some drugs can cause tingling and loss of sensation in the fingers and/or toes, and muscle weakness in the legs. If this happens, tell your doctor or nurse before your next treatment. Your treatment may need to be changed or the problem carefully monitored.

Change in hearing

Some chemotherapy drugs can affect your hearing. They may cause a loss in the ability to hear high-pitched sound, and can cause a continuous ringing noise in the ears, known as tinnitus. If you notice any change in your hearing, tell your doctor.

Skin rash/pain

If your skin becomes red or sore in the area where an intravenous device was used, tell your doctor or nurse immediately.

Chemotherapy side effects that are common to all treatments are addressed on pages 32 to 37.

Targeted therapies – managing side effects

Targeted therapies interfere with cancer cell growth and reproduction in different ways. The drug is distributed throughout the body and despite its selective mechanism of action it can interfere with normal cells as well. This is the cause of possible side effects. If you experience severe targeted therapy side effects it is important you tell your doctor so the treatment can be stopped until settled. A dose reduction can then be considered.



8. Treatment Side Effects and Management

Skin toxicity/rashes

Skin toxicity from targeted therapies is most likely to occur in the early days of treatment. It can appear as initially redness, with slight flaking skin around the eyebrows and hairline; on your face, upper chest and back; and then develop into a pinhead-sized white raised sore.

Tell your doctor about changes in your skin such as cracks, blisters, moist areas, rashes, infections or peeling, and any changes to your nails.

Some chemotherapy drugs, such as cetuximab and erlotinib, target the epidermal growth factor receptor (EGFR). A side effect of targeting this receptor is inflammation of the skin causing an acne-like rash that is temporary and will go away once treatment stops.

If you have a serious reaction to the EGFR treatment, talk with your doctor. They can prescribe an antihistamine to reduce the inflammation or suggest you use a corticosteroid cream. You may also be given a course of antibiotics.

Managing skin rashes:

- Use the same measures as for dry skin (listed on page 37).
- Don't shave every day. Use an electric shaver instead of a blade where possible. Don't use a razor blade on the treatment area.

- If you continue to use make-up, ensure it is dermatologist-approved.
- Remove make-up with a gentle liquid cleanser.
- Although it may seem like acne, it is not. Avoid all over-the-counter acne-related treatments.

Nail toxicity

Targeted therapies may cause nail toxicity. This is experienced as inflammation, pain and redness of the nail bed.

Managing nail toxicity

- Cut your nails carefully and evenly.
- Do not wear tight shoes and, where appropriate, wear cotton socks.
- There are many creams for this particular side effect. In some cases, your doctor may prescribe an antibiotic medication. It's important to discuss these side effects and possible solutions with your doctor.

Targeted therapy side effects that are common to all treatments are addressed on pages 32 to 37.

Chapter Summary

- ▷ The treatments for lung cancer can cause temporary side effects.
- ▷ Possible side effects common to radiation, chemotherapy and targeted therapy treatments include effects on the blood and immune system (such as anaemia and infections), fatigue, nausea and vomiting, constipation, diarrhoea and itchy or dry skin.
- ▷ Radiotherapy side effects can vary. You may experience localised burning at the application site, scarring, shortness of breath and neck and chest problems.
- ▷ Most chemotherapy drugs cause side effects, with the most common including nausea, fatigue, hair loss, skin rashes and mouth sores.
- ▷ In addition to nausea, diarrhoea and fatigue, targeted therapies can cause skin and nail toxicity.

9. Accessing New Treatments via Clinical Trials

Clinical trials are research studies that test new and potentially better ways of improving peoples' health. They are an important process to assess whether promising approaches to prevention, diagnosis and treatment are possible, safe, and effective in humans. Some trials also look at ways of enhancing a person's quality of life.

Clinical trials for cancer treatments are the final stages of a long and careful process that often starts many years earlier. Trials are the link between scientific discoveries made in the laboratory and making new treatments available for people with cancer.

Why clinical trials are important

A new treatment can only become standard treatment if it's proven safe and effective in a clinical trial. For this reason, clinical trials are essential for progressing improved treatments and care of people who have cancer. Many of the most effective treatments used today were trialled clinically in the past 30 years.

How clinical trials help people with cancer

Taking part in a clinical trial can improve the care of people with cancer.

People who take part in a clinical trial may respond better to treatment than those on standard treatment regimes. This is partly because trial participants must be fit and able to comply with treatment. They also receive more personalised care and attention from their research nurses and treating doctors. Their treatments, tests and follow-up abide by strict plans and guidelines, and they get extra information about their disease and treatment.

These additional care benefits for those involved with a clinical trial are the same for people whether they are in a control group (which receives the best standard treatment) or in the experimental group (which receives the new treatment being tested).

How clinical trials work

Each trial tries to answer specific questions that will contribute to finding new and better ways of helping people affected by cancer. However, for any new treatment three standard questions must be answered before the treatment can be used widely.

1. How should the new treatment be given or done?
2. Does the new treatment seem to work?
3. Is the new treatment better than the best current treatment?

Three separate and different trials – known as Phase 1, Phase 2 and Phase 3 clinical trials – are performed to answer these three questions sequentially.

Trials not only measure the effects of a new treatment on cancer, but also its wider impacts on a person's life. Researchers often ask participants to fill in questionnaires to measure the impact of a treatment on their quality of life. In these questionnaires, they answer questions about how they feel and how they are able to carry out everyday tasks. These effects are compared with those of other treatments.

How to find a clinical trial

Talk to your doctor if you would like to take part in a clinical trial. Your doctor may be involved in a suitable trial, know of one being done elsewhere, or if not, may be able to help you find one. If you hear of, or read about a clinical trial, for your type of lung cancer ask your doctor for more information.



9. Accessing New Treatments via Clinical Trials

Trial phases

Phase 1

- The first study that involves people.
- Looks at the best way to deliver a new treatment, how often, and if it involves medication – what dosage is safe.
- Only involves a small number of people.

Phase 2

- Continues to test the safety of the treatment.
- Assesses how well the new treatment seems to work.
- Involves about 50 people.

Phase 3

- Compares a new treatment to the best standard treatment, to work out which is best.
- Assigns people at random to receive either the new treatment or the best standard treatment.
- Usually involves between hundreds to thousands of people.

Keep in mind that clinical trials are not run at every treatment centre, so you might have to travel to a different location, including interstate, to take part in one.

Is a trial suitable for you

Your doctor may suggest you enter a clinical trial. This would be only after you have been carefully assessed and the trial is believed to be suitable for you. If the trial is not suitable, you will be offered the best treatment available.

If you want to consider taking part, your doctor must explain the trial to you and make sure you understand it completely. Your treating doctor should answer any questions you have about the trial.



If you're unsure, ask your doctor about someone else you can talk to about the trial. You can also seek a second opinion about the trial and other options. You should only agree to participate in a trial when you understand all you need to know about it.

Informed decision-making

Informed decision-making is required by law and is an essential part of being in a clinical trial. It means you should only be enrolled in a clinical trial after you understand the trial fully and have given your consent in writing.

Doctors follow guidelines to make sure they provide all the information you need. If you're considering a trial, you should be given a participant information sheet (fact sheet) about the trial. This should explain everything you need to know about the trial and treatment.

You should be given a full explanation of the treatment proposed for you in the trial. Then you can discuss this with your doctor or nurse. Having all this information should enable you to decide whether you wish to participate in the trial.

If you choose to participate, you will be asked to sign an informed consent form before entering the trial. A copy of this form will be given to you for your records. This is a standard part of every clinical trial.

9. Accessing New Treatments via Clinical Trials

The informed consent form will provide the following information:

- the aim of the treatment;
- what the treatments are and how often they are given;
- possible alternative treatments;
- risks and benefits of each treatment;
- any information you may need to decide whether or not to take part;
- your rights as a participant in the trial; and
- contact people.

Your role in a clinical trial

If you participate in a clinical trial, you will be watched closely and detailed records will be kept. You may have more examinations and tests than are usually given for the standard treatment. You also may be asked to answer questions about how you're feeling – your quality of life, as previously mentioned.

These additional tests and observations can have their own risks, benefits and inconveniences. However, they provide crucial information about your progress and the effects of the treatment.

During the trial, if it's clear that a treatment is not in your best interest, for example if it isn't working or if you have severe side effects, you or your doctor can stop the treatment at any time.

Always remember, the choice to join the trial is yours and you can withdraw at any time. Withdrawal will not affect your future care and you will return to receiving the standard treatment for your type of cancer.

What are the costs and who pays?

Taking part in a clinical trial will not cost you more money.

Research funding organisations such as the Cancer Council and the National Health and Medical Research Council (NHMRC) or the companies developing the treatments (such as drug companies and device manufacturers) usually fund clinical trials.

The trial organisers cover the cost of any extra tests or treatments involved in the trial that are not part of standard care. In many cases, they also provide funds to pay for some or all of the extra work involved for doctors, nurses and other medical staff.

Chapter Summary

- ▷ You may have an opportunity to access new treatments that are being trialled for their safety and efficacy in treating cancer in humans.
- ▷ Clinical trials are conducted in three phases.
- ▷ Additional benefits of taking part in a clinical trial include more personalised care and attention from research nurses and treating doctors.
- ▷ If you would like to take part in a clinical trial, talk to your doctor. They must explain the trial to you and make sure you understand it completely.
- ▷ Clinical trial participants are watched closely and detailed records kept. They may require more examinations and tests than for the standard treatment as well as being asked to answer questions about their quality of life.
- ▷ Taking part in a trial does not cost a patient any more than standard treatment.



10. Palliative and Supportive Care

Palliative and supportive care allows people with advanced cancer to enhance their quality of life in a way that is meaningful to them. It also supports families and carers in their adjustments to some of the lifestyle changes they may have to face.

Role of palliative care

Palliative care is designed to:

- help you achieve and maintain the best quality of life you can for as long as possible;
- make sure your physical, practical, emotional and spiritual needs are catered for;
- control symptoms that may arise during the course of cancer, including symptoms that may arise while you may be receiving anti-cancer treatments;
- help you feel in control of your situation; and
- make the time you have as valuable as it can be for you and your family.

Palliative care does not automatically mean 'end of life care'. While end of life care can be an important aspect of palliative care, with improved treatments to help stop the spread of cancer and relieve side effects, some people receive palliative care alongside treatments directed at the cancer itself for several years in order to live for as long as possible in the most satisfying way within the limits of their illness. Many aspects of palliative care – symptom management and family support for example – may be addressed by your GP or your multi-disciplinary team. Specialist palliative care services are also available and can be accessed at the same time as other multi-disciplinary care.

The focus of palliative care is enhancing your quality of life. Palliative care can help guide you to resources

that are available for you in your preferred place of care and, if needed, assist you with end of life issues.

How palliative care helps patients

The primary objective of palliative care is to make life easier for you, your family and/or carer.

Palliative care needs vary and often a team is needed to address the array of needs that can arise. Depending on your needs, the care offered may include:

- assisting you with advice about symptom management;
- supporting your family and helping them to look after you more effectively;
- helping you plan for your future needs (such as community supports, the type of care needed, and where you will receive treatment);
- checking in with you at home via telephone or sometimes with house visits;
- providing emotional support to you and your family including with issues of loss and grief; and
- talking with you about your specific goals and plans and also, if you feel it is appropriate, about your end of life wishes.

Accessing palliative care

It is advisable to access palliative care early - being able to deal with problems or issues earlier rather than later can help reduce stress for both you and your family.

GPs or community nurses usually coordinate palliative care. If your needs are complex, they may refer you to a specialist palliative care team.

The specialist palliative care team consults with your GP, nurse and, if appropriate, your oncology specialist team about your care and treatment. You

may want your key family members and/or carer to take part in palliative care discussions as they often provide most of the ongoing, day-to-day care.

Palliative care can be provided as a part of your care at home, in hospital, at a palliative care unit, or hospice, and you can move between these settings if your needs change. Access to specialist services varies across Australia but referral to these specialists is most commonly made through your GP or oncology team. Regardless of what stage your cancer is at, and whether the medical aspects of it are coordinated by a GP or specialist, the aim of palliative care is to continually assess your changing needs and adjust your care to respond to those needs as required.

Both you and your family/ carer can be consulted on your changing needs and the team will suggest choices to help you remain independent for as long as possible.

Paying for palliative care

The Commonwealth and State governments fund many of the core palliative care services. This means you can access many of the services at no charge through the public health system – whether you receive care at home or in a public hospital setting. Some private hospitals also have access to a palliative care specialist who can assist you with your symptoms or assist in referring you to a community palliative care team.



Sometimes you may need to contribute to the costs of care, such as:

- hiring specialised equipment for use at home;
- personal nursing staff if you elect to stay at home and require round-the-clock assistance;
- massage therapy used with physiotherapy services; and
- an excess if your health insurance covers palliative care and you choose to go to a private hospital.

Chapter Summary

- ▷ Palliative and supportive care is treatment that helps improve quality of life. It can be used at different stages of your lung cancer journey – it is not just for end of life care.
- ▷ This type of care is provided in homes, hospitals, palliative care units, and in hospices.
- ▷ Your GP or community nurse can coordinate palliative care and the palliative care specialist teams generally seek to continually liaise with your GP or multidisciplinary team.
- ▷ A palliative care team will work with you to make life easier for you, your family and/or carer.
- ▷ Many core palliative care services are provided free of charge through the public health system.



11. Living Well with Lung Cancer

Lung cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and improve wellbeing. Addressing changes in your emotions and relationships early on is also important.

Nutrition and healthy eating

Cancer and its treatment can place extra demands on your body, which makes eating a variety of healthy foods important. Good nutrition – giving your body the food it needs to keep working properly – helps you:

- cope better with treatment side effects and to recover sooner;
- heal faster from wounds and damaged tissues; and
- improve your body's natural defences, so you're better able to fight infection.

Throughout the phases of cancer treatment and recovery, it's essential to adapt what you eat to cope with your body's changing nutritional needs.

Phase 1 – Cancer treatment

Eating a healthy diet in the lead-up and during cancer treatment will help you keep up your strength. Plan ahead to make eating during the treatment phase as easy as possible, for example, ask a friend or relative to do your grocery shopping or to make up some frozen meals that you can reheat if you don't feel like cooking.

You may need more energy (measured in kilojoules/calories). So eat small frequent meals or snacks (called 'grazing') rather than having three large meals each day.

If you start to lose weight, eat extra nutritious snacks or drinks (such as dairy products).

If possible, do some light physical activity, such as walking, to improve your appetite, help digestion and prevent constipation.

Phase 2 – Recovering from treatment

If you're recovering from cancer treatment, you need to eat a variety of foods and do some physical activity to rebuild your muscles and repair any problems that may have resulted from treatment.

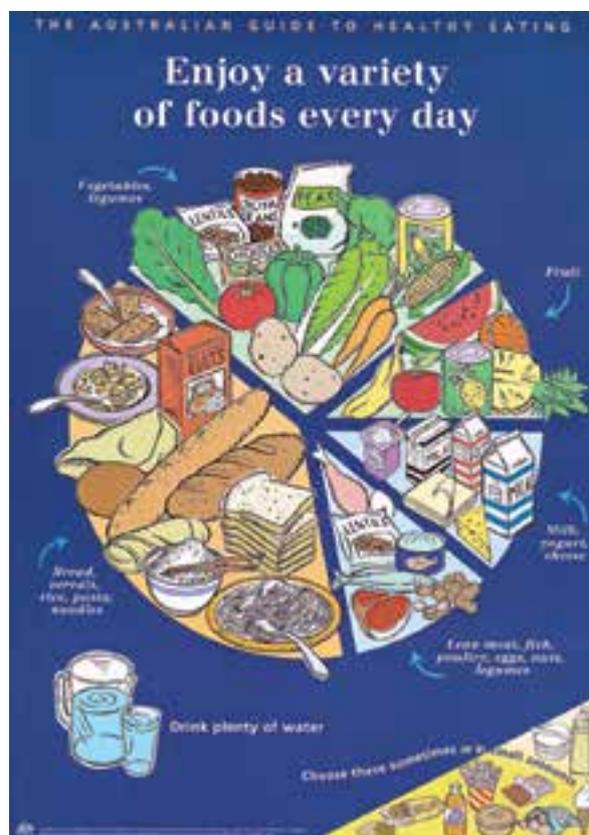


Illustration source: Commonwealth of Australia 1998. *The Australian Guide to Healthy Eating*.

Phase 3 – Preventing cancer recurrence/new cancers

To improve your body's defence against the recurrence of cancer and to minimise the risk of new cancers, you should eat healthily, maintain a healthy body weight and undertake light physical activity.

You should also maintain a healthy diet of fruits and vegetables. Aim to eat two serves of fruit and five serves of vegetables each day.

Phase 4 – Living with advanced cancer

For people who have advanced cancer, good nutrition can help to maintain quality of life. As your nutritional needs change, adjust your food choices and eating patterns accordingly.

Medications and physical activity can boost your appetite, and nutrition supplements may help if you can't eat. Further information on these supplements and medications is available from your doctor, palliative care specialist or dietitian.

Good food hygiene

Good food hygiene is important for everyone. However, if your white cell count is low, particularly during chemotherapy treatment, you will need to take extra care with preparing food. Most food poisoning results from improper handling and storage of food.

You can protect yourself by:

- choosing freshly cooked and freshly prepared foods;
- always thawing frozen food in the fridge or defrosting in the microwave;
- keeping raw meat covered, and keeping it separate from cooked food or ready-to-eat foods;
- thoroughly washing your hands, knives and cutting boards between handling raw food and ready-to-eat foods;
- taking extra care when ordering take-away or pre-made food; and
- avoiding raw, rare or partially cooked fish, meats, poultry or eggs.



Dietitians

A dietitian can help you with any nutrition concerns. They are available in all public hospitals, some private hospitals and community health centres often also have a dietitian.

Cancer patients are eligible for a Medicare rebate for a consultation with an accredited practicing dietitian under the Enhanced Primary Care plan, if they have been referred by a GP. Some private health insurers provide a rebate as well.

The Dietitians Association of Australia (DAA) can direct you to an accredited practicing dietitian in your area or one who has experience with particular problems. Visit the DAA website, www.daa.asn.au or call **1800 812 942**.

Being active

There are many benefits to being active. Exercise can boost energy levels, decrease fatigue, increase strength, and relieve stress as well as lower anxiety and depression.

Physical activity should be started slowly and increased gradually. Each person's situation is different and the amount of activity will vary from person to person.

Here are some suggestions for being as active as you can.

- Walking is great exercise. You do not have to join a gym to be more active.



11. Living Well with Lung Cancer

- Walk with a friend or join a walking group.
- Do some simple stretching exercises while watching television.
- Do vigorous housework like vacuuming or mowing the lawn.
- Get out of the house and do some gardening.
- Take the children or grandchildren to the park.

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

Quitting smoking

Smoking is addictive and this is the main reason why smokers continue to smoke even though many of them have tried to quit. Your doctors understand and will consider this when caring for you. They should not regard you negatively because you are (or were) a smoker.

Research has shown that people who quit smoking, even after a diagnosis of lung cancer, will improve their chances of responding to treatment. In recent studies, it was found that continuing to smoke during chemotherapy may reduce the effectiveness of the treatment.

If you need help to quit smoking, call Quitline on **13 78 48**. You can also visit the Quit Now website at www.quitnow.gov.au.

Treatment compliance

Anything you take or use for therapeutic benefit is a medicine. This includes prescribed medications from your doctor, over-the-counter medicines from the pharmacy, the supermarket or another store. It also extends to herbal remedies, vitamins and other supplements.

All medicines have potential benefits and risks, and sometimes interact with each other; which is why it's important that you discuss all the medicines you're using with your health professionals.

Only take prescribed amounts

Always follow instructions from your doctor or pharmacist and carefully read the labels and packaging of your medicines.

You can get further information on your medicines by reading the Consumer Medicine Information (CMI) leaflets that are available for prescription and pharmacist-only medicines. You also find printable CMI leaflets at the NPS Medicinewise website: www.nps.org.au.

You may have unwanted effects from your medicines if you don't take or use them as directed. For example, taking or using more medicine than you're prescribed or recommended will not necessarily make it more effective for you. Doing this is more likely to cause you side effects or serious harm.

Know the active ingredient

Most medicines have two names – the 'active ingredient' and the 'brand' name. The active ingredient identifies the chemical in the medicine that makes it work. The brand name is the name given to the medicine by its manufacturer.

The same active ingredient can be found in more than one medicine under different brand names. Always check the active ingredient every time you get a medicine to avoid doubling up and taking too much. This can happen when you get a different brand of the same medicine from a doctor or pharmacist, or when you leave hospital, or when you purchase a medicine yourself that has the same active ingredient as your other medicines.

By knowing the active ingredient, you also can check that you're not taking a medicine that you're allergic to or shouldn't be taking along with your other medicines.

Knowing the active ingredient also enables you to identify suitable alternatives to your medicines when travelling overseas. In addition, it helps you understand the packaging and labelling of medicines you get from a hospital, where the active ingredient is used to prescribe and dispense medicines.

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.

Complementary therapies

Complementary therapies are used along with conventional treatments. They help some people address a wide range of challenges beyond medical treatment for cancer.

These therapies are sometimes called 'complementary medicine', 'holistic therapies', 'natural therapies', 'traditional therapies' or 'traditional medicine'. Integrative medicine is the term used when conventional treatments are combined with evidence-based complementary therapies.

Complementary therapies may help you to cope better with symptoms of cancer and side effects from conventional treatments. These therapies also may improve your wellbeing throughout the different phases of your treatment and recovery from cancer and may provide comfort and relief for people having palliative care.

Examples of complementary therapies include acupuncture, massage, aromatherapy, meditation, counselling, nutrition, herbal medicine, and reflexology. Not all complementary therapies have been scientifically proven to work and their safety and effectiveness is not always clear. However, there is an increasing amount of research and clinical trials focusing on understanding the value of these therapies and their use in helping people with cancer.

It's important to know that complementary therapies are usually safe when you see qualified practitioners who understand the needs of people with cancer. However, you should weigh up the pros and cons of using these therapies, and discuss your decision with your doctor, to minimise the risk of any problems.

For more information, contact Cancer Council on **131120** for a copy of Understanding Complementary Therapies or download from www.cancercouncil.com.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, contact Lung Foundation Australia on **1800 654 301** or visit the Look Good...Feel Better website at www.lgfb.org.au.

Relationships with others

The strong emotions you experience because of cancer may affect your relationships. Your experiences may cause you to develop a new outlook on your values, priorities, and life in general. Sharing those thoughts and feelings with your family, friends and work colleagues may strengthen your relationships.

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

While you're giving yourself time to adjust to cancer, do the same for your friends and family. Everyone will react in a different way. They may put on a happy face, play down your anxiety, or even ignore you. They also are 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.

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, the way you and your partner communicate, and your self-confidence.



11. Living Well with Lung Cancer

Some people face cancer without the support of a partner. If you're single, you may choose not to be in a monogamous or long-term relationship or, you may be searching for a new partner. It can be difficult to decide when to talk about the cancer.

Knowing the potential challenges and addressing them will help you adjust to these changes. Sexual intercourse may not always be possible during treatment, but closeness and sharing are vital to a healthy relationship.

Contraception

When receiving certain treatments, such as chemotherapy, your doctor may advise you to use contraception or abstain from sex for 48 hours after treatment to protect your partner from chemicals that may be in your body fluids. Talk to your medical oncologist or other appropriate team member for more information.

Chapter Summary

- ▷ To live well with lung cancer, there is a range of simple steps you can take such as complying with your treatment regime and eating well and exercising to cope with the physical and emotional toll of the disease.
- ▷ Good nutrition is important to recovering from treatment and dealing with cancer. Your nutritional needs will vary during treatment, in recovery, and post treatment or when living with advanced cancer. A dietitian can help you with each stage.
- ▷ During treatment, you will need to be especially careful about good food hygiene.
- ▷ Physical activity can help you deal with the symptoms of lung cancer as well as improve the recovery time from treatment.
- ▷ If you're a smoker, you can improve your chances of responding to treatment if you quit. However, because smoking is an addiction, you're more likely to succeed with help.
- ▷ Comply with prescribed medications and only take the prescribed amounts. Knowing the active ingredient will help you always take the correct dosage and be able to identify alternatives when travelling.
- ▷ Complementary therapies may help you to cope better with symptoms of cancer. Always discuss using these therapies with your doctor to make sure they can be combined safely with conventional treatment.
- ▷ You may find your self-esteem knocked about by cancer treatment. However, there are practical ways to deal with physical changes resulting from treatment.
- ▷ Address early on any changes in your emotions or feelings with your family and friends.
- ▷ Your sexuality may be affected by cancer, it will help you to understand and address any potential impact this has on your life. You also may have to use contraception at times during treatment.

12. Making Decisions about Treatment

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

Waiting for test results and for treatment to begin can be difficult. Some people feel overwhelmed by information, while others want as much information as they can find. Either way, making sure you understand enough about your illness, the treatment options and side effects will help you make your own decisions.

If 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. In this situation, it may help to contact a lung cancer nurse or see a hospital social worker for help and support. If you have a partner, you may want to talk with them about your treatment options. You can also talk to friends and family.

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

Some people with more advanced cancer will choose treatment, even if it offers only a small chance of cure. Others may refuse treatment if the side effects outweigh the benefits so that they retain the best possible quality of life. Another option people choose is to receive treatment that while not curing the cancer will make them feel as well as possible for as long as possible. Always remember that you have the right to accept or refuse any treatment.

Talking with doctors

When your doctor first tells you that you have cancer, it's very stressful and you may not remember many details about what you're told. You may want to see the doctor several 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 also can check the meaning of words in the Glossary (see page 69).

Before seeing your doctor, it may help to write down your questions (see page 68 for a list of example questions for your doctor). Taking notes or recording the discussion can help too. Many people like to have a family member or friend with them to take part in the discussion with their doctor, to take notes or simply to listen.

A second opinion

For some people, it's important to speak to more than one doctor regarding their diagnosis and recommended treatment plan. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor.

Speak to your doctor if you would like a second opinion. They are used to such requests and can refer you to another specialist as well as send your initial results to that person.

In a situation where the second specialist provides an opinion that differs from your initial doctor, you may wish to seek a third opinion or discuss the differing opinions with other members of your multidisciplinary team. Ultimately, it will be your decision as to which specialist's opinion you feel is right for you.



12. Making Decisions about Treatment

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 you can ask for clarification.

- What type of lung cancer do I have?
- How extensive is my cancer?
- 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?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? How much will it affect what I can do? How much will it cost?
- Will I have to stay in hospital?
- Will the treatment affect my sex life?
- Would palliative care be useful for me?
- Are there any complementary therapies that might help me?
- Are there any clinical trials of new treatments for my type of lung cancer?
- How frequently will I have check-ups?

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

End-of-life decision making

While your health care professionals will do everything they can to cure your lung cancer, factors such as the stage of the cancer at diagnosis, sometimes mean that their best efforts cannot achieve a cure. For some people with advanced lung cancer, treatment can keep the disease under control for months or years without curing it. Treatment also can help control symptoms such as pain to make life more comfortable.

Your right to stop treatment

Some people with advanced cancer decide to stop cancer treatment and choose to have palliative care instead. This is a personal decision that you need to communicate to your family and health professionals.

In legal terms, if you want to refuse medical treatment, you must fully understand the nature of the treatment proposed and the consequences of not having treatment. You can refuse each treatment separately; you don't have to accept treatment on an all-or-nothing basis.

You can complete a refusal of medical treatment certificate outlining your wishes that your doctors must follow.

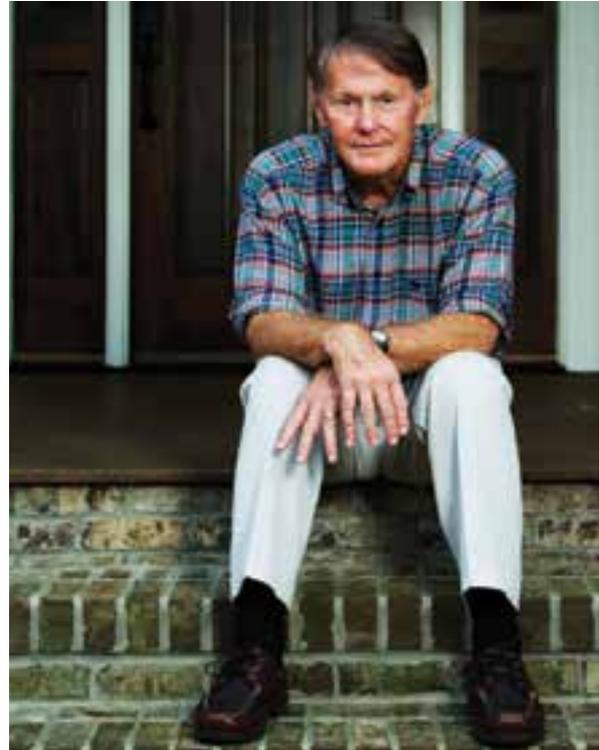
Your right to keep trying

It's your right to request that treatment continues. Keep in mind that your doctor also has a right to refuse to keep treating you if the treatment will do more harm than good.

You may want to get a second opinion to explore your options. Again, it's important to communicate your wishes clearly to your family and carers so they can support you.

Making your wishes clear

Many people who have cancer think about what type of medical care they want to receive at the end-of-life. It's important to write down what you want, in case you become incapacitated. You may create an Advance Health Care Directive and/or an Enduring Power of Attorney. Your doctor can consult these documents rather than speak to your next of kin (see Chapter 13 for more information).



Chapter Summary

- ▷ Take the time to consider the type of treatment you want. To make an informed decision, you will need to understand enough about your illness, the treatment options and the side effects.
- ▷ Talk about your treatment options with your GP and/or your medical team. It can help to make a list of questions before meeting with them and to take a family member or friend.
- ▷ A second opinion from another specialist may be beneficial for you. Your doctor can refer you to another specialist.
- ▷ If your cancer is incurable, there may be treatments to control the disease as well as the symptoms. You have the right to either refuse medical treatment or request treatment to continue.
- ▷ Help make your 'end-of-life' care wishes clear with an Advance Health Care Directive and/or Enduring Power of Attorney.



13. Financial and Legal Considerations

When first diagnosed with any major illness, particularly one that is chronic and life altering like lung cancer, legal issues are often the last things you consider. Unfortunately, by neglecting your legal rights and options to protect you and your family, you can make those daunting legal issues become even more complicated.

There are some simple steps you can take to ensure you have access to any financial support you may need and to ensure that your family is taken care of in the future – even if you're unable to work.

Superannuation benefits

- Contributions by your employer and you
- Insurance coverage for death and disablement

Accessing superannuation and insurance

All working Australians have a superannuation fund to which their employer must contribute during the course of their working life. Some people also elect to contribute further to their superannuation.

You can access your superannuation before retirement age in the event of a serious illness like lung cancer. All superannuation funds also have a component of insurance to help you if you're unable to work because of serious illness.

All policies are different. Some funds offer lump sum benefits if you become totally and permanently disabled or partially and permanently disabled.

Some funds provide temporary cover if you're off work for only a short period of time by paying all or a percentage of your income while you're unable to work.

You can access:

- lump sum benefits;
- income protection and/or
- death benefits.

You do not need to show fault on the part of anyone or that the cause of your illness was beyond your control. The mere fact that you have the illness and that it stops you from working is usually enough.

Generally, benefits are available for people of working age. Different funds have different rules and you should carefully check your own circumstances and seek advice.

Contact your superannuation fund to find out what benefits are available. You should critically analyse the information you're given by the superannuation fund manager or insurer. Because of the complexities involved and the different considerations that apply in your own set of circumstances, a one-size-fits-all approach often means some people will miss-out on their entitlements.

Legal advice can help ensure the information you receive is correct and assist you to access all your entitlements. The Cancer Council's Financial and Legal Advice section may be of help to you in this area. However, it's also advisable to see the social worker aligned to your treating specialists. Palliative care teams have a social worker who can provide advice and support.

The terms and conditions applying to insurance components are sometimes straightforward but often they are more complex than they look.

Entitlements in the workplace

Many people with lung cancer find their symptoms and/or treatment or side effects affect their ability to attend work or their ability to undertake their work duties.

All employees are entitled to some measure of sick or unpaid leave in the event of a serious illness. The sources of this entitlement are many and varied and range from legislation through to written contracts of employment.

General protections are available to you in the workplace if you're diagnosed with an illness like lung cancer and need to access leave or have some reasonable adjustment made to enable you to continue working.

An employer cannot treat you unfairly or take adverse action against you merely because you have a chronic illness or are attempting to exercise a workplace right like taking sick leave. If an employer does take adverse action in these circumstances, you're entitled to seek court orders to restore the status quo, as well as requesting that the employer be subject to a fine for breaching legislation.

Whether you're an employee, an independent contractor or in business, a serious illness should not be used by an employer or head contractor as an excuse to disadvantage you or treat you differently.

Anti-discrimination laws across Australia are designed to recognise people with illnesses who are at a disadvantage and should be treated fairly. An employer must make reasonable adjustments in the workplace to assist you to conduct your work duties to the best of your ability having regard to the impacts of your illness.



Ensuring access to financial support

There are many community-based and government organisations that can provide financial and other support in your time of need.

You do not have to accept adverse decisions made in relation to your entitlements to financial assistance or services. Often there is a process of review and appeal in relation to those decisions, particularly administrative decisions made by government. The courts have a general power of review of those decisions to ensure that administrative decision-makers exercise their powers in a just and fair manner.

As a member of a community organisation or other support service, your membership terms and conditions also may enable you to review or appeal decisions made that are adverse to your interests.

You should seek legal advice about your rights in relation to any adverse decision.

13. Financial and Legal Considerations

Wills: protecting your assets for your family

It is essential that your intentions regarding distribution of property, and your wishes in relation to the continuation of treatment, are known and documented. A will is a document that identifies your intentions and provides instructions for the distribution of your assets when you die.

Depending on their relationship to you, family members will accrue rights under the will or in accordance with the law and sometimes those rights can conflict. Having a clear and up-to-date will is vital to avoid any conflict.

How assets are passed on via a will can affect the beneficiary of those assets. Development of appropriate testamentary trusts will assist the beneficiaries to access those assets and assist with tax minimisation.

Testamentary discretionary trusts are particularly recommended if the beneficiary who will receive the assets:

- has a disability;
- is poor at handling his/her finances;
- practices in a profession which has a high risk of litigation;
- is in a high tax bracket; or
- has a history of bankruptcy.

In the event of conflict between beneficiaries or potential beneficiaries of an estate, often there are significant emotions at play. Good planning and open communication in the preparation of a will often avoids conflict or confusion.

Whenever your personal circumstances change, you should review, and if necessary, update your will.

Advance Health Directives and Enduring Powers of Attorney

For those living with lung cancer, it is important to plan-ahead. This will ensure your family members and/or carer are aware of your wishes in relation to ongoing treatment.

Advance Health Care Directive

You have the ability to document an Advance Health Directive for your loved ones as to your wishes in the event that you lose capacity to make decisions because of your illness or while undergoing treatment.

Sometimes called a living will, this legal document outlines your specific wishes for future medical care. It comes into effect only if you're unable to make your own decisions.

An Advanced Health Directive can look at issues including:

- what level and extent of treatment you wish to undergo;
- who should have the power to make decisions on your behalf;
- special medical conditions your doctor or other medical staff should know about;
- religious, spiritual or cultural beliefs that may affect treatment;
- considerations relating to resuscitation or the withholding or withdrawing of life sustaining measures; and
- your wishes relating to the donation of organs in the event of your death.

You should keep a copy of your Advance Health Care Directive and give a copy to your GP, oncologist, enduring guardian and a family member or friend. You can ask for it to be placed in your medical record and for your solicitor to keep a copy.

Enduring Power of Attorney (or enduring guardian)

An Enduring Power of Attorney appoints a responsible and trusted person to make decisions on your behalf. The guardian only steps in if you become unable to make your own decisions.

You can appoint one or more people over 18 years old to be your enduring guardian, but they must not be in paid employment to provide you medical care.

In combination with an Advance Health Directive Enduring, an Enduring Power of Attorney ensures your wishes are met and maintained.



Chapter Summary

- ▷ To ensure you have access to available financial support, and for the sake of your family, address any outstanding financial and legal issues.
- ▷ Look at your superannuation policy to see what insurance coverage and financial benefits you can claim.
- ▷ Lung cancer may affect your ability to attend work or to undertake your work duties. However, you should be entitled to some measure of sick or unpaid leave. There are also general protections to ensure you're not discriminated against and so that you can continue working in a limited capacity.
- ▷ Avoid family conflicts by leaving a will that identifies your intentions and provides instructions for the distribution of your assets when you die.
- ▷ Document an Advance Health Directive as well as appoint an Enduring Power of Attorney to ensure your wishes are met and maintained if you lose the capacity to make decisions.

14. Seeking Support

When you're first diagnosed with lung cancer, and throughout the different phases of your treatment and recovery, it's 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. You can also talk to:

- members of your treatment team;
- a counsellor, social worker or psychologist;
- your religious or spiritual adviser;
- a patient support group; or
- Lung Foundation Australia.

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 know what to say to you. This can be difficult and it may make you feel lonely.

“ To begin with I didn't know if the support group was for me but I gained a lot strength and inspiration from other peoples' stories and experiences. ”

Jenny

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.

Lung Foundation Australia can provide information about coping with your emotions – call **1800 654 301**.

Emotional support

Talk to someone who's been there

Getting in touch with other people who have been through a similar experience with lung cancer can be beneficial. In a support setting, 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.

Patient support groups

People in a patient support group share common interests and experiences. People who have a lung condition along with their carers and families get together regularly as a group to share information and discuss ways to cope with the challenges of living with a lung condition.

Patient support groups offer a welcoming, informal environment and the opportunity to participate in many different types of activities that may include:

- regular meetings;
- guest speakers providing information on a range of topics;
- receiving and distributing lung health information;
- education and information days;

- exercise programs;
- social or recreational activities;
- group newsletters; and
- member-to-member support (through telephone calls, hospital and home visits).

Ask your nurse or social worker to tell you about support groups in your area or call Lung Foundation Australia on **1800 654 301**.

Telephone support groups

Lung Foundation Australia runs Lung Cancer Telephone Support Groups to help connect patients and carers throughout Australia with other people in a similar situation.

The telephone support groups offer a unique opportunity to access emotional support and information as well as share your experiences.

To find out more information or to join a telephone support group today, please call Lung Foundation Australia on **1800 654 301**.

Finding emotional support in your community

There are many ways to contact others for mutual support and to share information.

- **Online information and discussion forums** – visit the Kylie Johnston Lung Cancer Network at www.kjlcn.org.au
- **Support groups** – held in community centres, hospitals or over the phone.
- **Personal support** – talk to someone else who has been through cancer treatment.

Practical and financial help

Having 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 call Lung Foundation Australia on **1800 654 301**.

Learning more about lung cancer

If you want to find out more about lung cancer, and how to cope with it, contact Lung Foundation Australia, the Cancer Council or your local hospital about education programs or seminars that are available. Programs cover a range of topics including, what cancer is, treatment, side effects, and support services. Attending a program also gives you the opportunity to meet other people affected by cancer.

14. Seeking Support

Psychological, social and counselling support

When you're diagnosed with lung cancer, suddenly you're faced with decisions and emotions you never thought you would have to deal with. The thought of lung cancer is frightening in different ways. Your first thoughts may be:

- How serious is this?
- Am I going to die?
- Will it be cured?
- Will I be able to do the things I usually do?

In the time after diagnosis, you may experience many different feelings. Common reactions are anxiety or fear, sadness, and sometimes anger. Such strong emotions can make you feel as if you're losing control of your emotions or your life. You may never have felt this way before and it can be overwhelming.

Throughout your journey with lung cancer, you will have to deal with many things for the first time. No matter how you're feeling, support services are available to you. If you speak to your GP or lung care nurse, they will refer you to someone who can help you with these feelings and help you to manage them.

Counsellor or psychologist:

- encourages you to talk about any fears, worries or conflicting emotions you may be feeling;
- helps you to work through feelings of loss or grief;
- can assist you and your partner with relationship issues;
- helps you resolve problems so that you can find more pleasure in your life;
- teaches you strategies to handle any anxiety you have;
- may show you meditation or relaxation exercises to help ease physical and emotional pain;
- can help you to communicate better with your family; and
- provides bereavement care to your family and carers.

“ There's only one piece of advice that I can offer another patient: whatever you do, don't give up hope. I am cancer-free today, and nobody really knows why (except for my wife, who firmly believes that all the paw-paw and mango I've eaten have made the difference). If it can happen to me, why can't it happen to you?” ”

Michael, 49 (diagnosed in 2007)

Pastoral carer or spiritual adviser:

- supports you in talking about any spiritual matters on your mind;
- reflects with you about your life and helps you search for its meaning (if appropriate);
- helps you to feel hopeful and develop ways to enjoy your life despite your illness;
- may organise special prayer services for you;
- can bring you into contact with other members of your faith; and
- may discuss general emotional issues, as many are trained counsellors.

Social worker:

- provides counselling and gives you and your family emotional support;
- discusses ways of coping and how to emotionally support your children;
- may help you to work out who among your friends, family and neighbours you can ask to form a support team;
- tells you about useful services such as home respite care, meal services, the mobility parking scheme, personal alarms, laundry services, and aged care services; and
- helps you access your entitled financial support.

Chapter Summary

- ▷ You don't need to face lung cancer alone, there are many people who can help support you through every aspect of treatment, recovery and living with the disease – practically, financially, emotionally and spiritually.
- ▷ Talking to someone who's been through, or is going through, lung cancer can help. Patient support groups provide a welcoming, informal environment to share common interests and experiences. Lung Foundation Australia runs lung cancer telephone support groups to connect patients and carers.
- ▷ Many services are available to help you practically and financially, these include government benefits and pensions and home care services.
- ▷ Learn more about lung cancer through educational programs and seminars available through your hospital and/or groups like Lung Foundation Australia and the Cancer Council.
- ▷ Counsellors, psychologists, pastoral or spiritual advisors and social workers can each provide varying degrees of emotional support and ways to help you deal with issues associated with your illness.

15. 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 the physical and emotional changes.

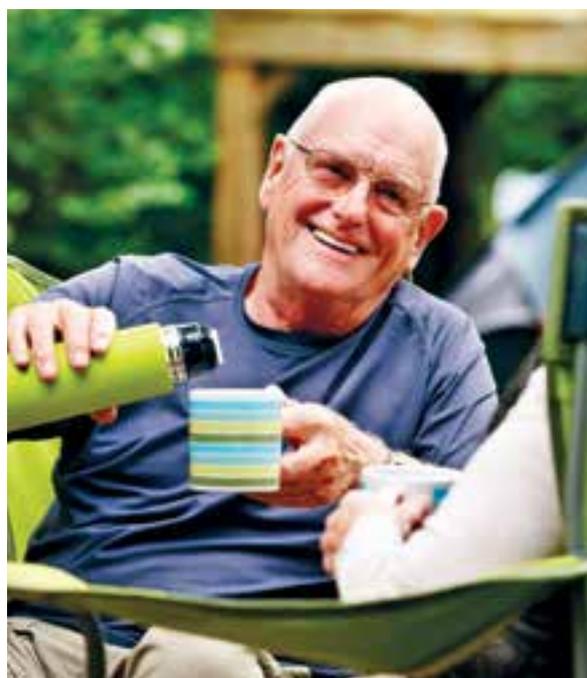
You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than secure. You might worry about every ache and pain and wonder if the cancer is coming back.

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

Post-treatment, many people also comment that 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;



- share your concerns with family and friends and tell them how to support you; and
- 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 counseling or medication may help you.

Case Study: Life after cancer for Michael

Michael was 49 when first diagnosed with lung cancer in 2007. He and his family were preparing to move to China when he began experiencing fatigue.

"I've had lung cancer twice. Before I became ill I was fit and strong. On each occasion, I began at a healthy 80 plus kilograms and then lost more than 20 kilograms. Each time I ended up looking like a skeleton with skin.

I had difficulty breathing before I had lung cancer and now, with only one lung, I'm usually short of breath.

I still have very little stamina and am awake for only twelve hours a day. However, from a mental perspective my world is a very different place.

It seems to me that before I was unwell I worried about things that really don't matter at all. The threat of dying prematurely has made me value what I have so much more...and as sad as my cancer experience has been I believe that it has enriched my children enormously."



16. Information for Carers

You may be reading this booklet because you're caring for someone with lung 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.

Caring for yourself

Caring can be rewarding but many carers also find it demanding, both physically and emotionally.

If you have been caring for someone for some time, you may feel exhausted. You may feel guilty about making time for yourself. However, looking after yourself can help relieve the stress and exhaustion of caring, and can reduce feelings of frustration and isolation.

Make time for yourself: Take some time every day, even if it's just a few moments, to do something for yourself and try to stay involved in activities you enjoy.

Care for your body: Eat healthy meals and snacks and exercise for 15-30 minutes a day. This will make you feel more energetic, help you to sleep better and improve your mood. Avoid using alcohol or cigarettes to deal with stress. These may make you feel better for a short time but will contribute to other problems.

Talk with family and friends: Talking about how you feel about caring may help you deal with these emotions, particularly if you're feeling angry (venting). If you feel uncomfortable talking to the person with cancer because you think they have enough to deal with already, it can be helpful to share your feelings with a friend, another family member, or other carers. You also could join a support group.



Visit www.kjlc.org.au for further information on the Lung Cancer Carer Telephone Group that meets each month.

Support

Support services such as Meals on Wheels or visiting nurses can help you in your role as a carer. Many organisations and groups can provide you with information and support. To learn more, contact Carers Australia on www.carersaustralia.com.au or **(02) 6122 9900**.

To find out more about different support services, call Lung Foundation Australia on **1800 654 301**.



Case Study: Irene's story

"When your partner gets a lung cancer diagnosis, your world comes crashing down.

You're lost. It's hard to breathe and your mind is racing a million miles an hour. You're heartbroken. You would do anything to be given more time with them. I remember thinking just how grateful I would be to have another two years together.

After treatment, my usually kind, introverted and helpful husband returned from hospital a horrid demanding monster. He went on a spending spree. He started screaming constantly with a level of aggression I'd never witnessed. Anything would set him off.

My husband's last radiology treatment finished just before my 40th birthday and as our relationship was not on track (there was an enormous level of resentment on both sides) we decided to do what we do best, travel. It worked.

Twenty-one months on from his last course of treatment, there is no tumour and our lung specialist told us that he thinks my husband's immune system has dealt with the cancer.

I still hate the responsibility of having to be a carer. I can't eat. I can't sleep. There have been times where I just can't get off the couch from mental exhaustion. However, I want my husband to be alive more than anything.

His cancer has made me stop fearing being alone or being able to take care of myself. It has made me much stronger. It has taught the children great home care skills. It has allowed me to be home when they come home from school. It has given us as a family time to have wonderful conversations. It has given us the opportunity to see the most amazing things."

17. Other Resources

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

Lung Foundation Australia's website has extensive resources on lung disease, patient support groups, professional resources and other initiatives, visit www.lungfoundation.com.au.

Call Lung Foundation Australia on **1800 654 301** for further information on lung cancer including a range of books, DVDs and medical journals that may be helpful for you.

Your local library also may have some relevant resources.

“*After I was diagnosed with lung cancer our computers ran hot. The research and discussions went on day and night. Both kids took time off work and became very knowledgeable about all aspects of lung cancer and its treatment.*”

Coleen, 60 (diagnosed in 2006)

Useful websites

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

Australian

Lung Foundation Australia:
www.lungfoundation.com.au

The Kylie Johnston Lung Cancer Network:
www.kjlcn.org.au

Asbestos Diseases Foundation of Australia:
www.adfa.org.au

Cancer Council Australia: www.cancer.org.au

Cancer Australia: www.canceraustralia.gov.au

Cancer Voices Australia:
www.cancervoicesaustralia.org.au

Health Insite – an Australian Government initiative:
www.healthinsite.gov.au

Commonwealth Department of Health and Ageing:
www.health.gov.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

Global Lung Cancer Coalition:
www.lungcancercoalition.org

18. About Lung Foundation Australia

Lung Foundation Australia is the leading charitable organisation dedicated to supporting people affected by lung disease in Australia.

Our vision is to ensure that lung health is a priority for all Australians. We achieve this through:

- promoting lung health;
- raising awareness of the impact and symptoms of lung disease;
- promoting targeted screening and early diagnosis;
- providing advocacy, education, and support for all people affected by lung disease;
- sponsoring medical and scientific research into lung disease; and
- working with and through other organisations.

Our initiatives to assist in reducing the impact of lung disease focus on the following key areas of activity:

- Lung Cancer National Program;
- LungNet Information and Support Centre;
- Chronic Obstructive Pulmonary Disease (COPD) National Program;
- Lungs in Action Program;
- Interstitial and Orphan (rare) Lung Disease Program; and the
- Chronic Cough Group.

For more information on these initiatives please visit www.lungfoundation.com.au or call **1800 654 301**.

How you can get involved

Lung Foundation Australia receives no on-going government funding for our core activities. We rely on funding from events, membership, bequests, projects, and donations from individuals, business and industry. There are three key ways you can get involved.

Take part in an event: Lung Foundation Australia holds education days in most states and November is Lung Health Awareness Month. Lung Foundation Australia also hosts 'Shine A Light on Lung Cancer' vigils throughout November.

Make a donation: every donation, whether large or small, makes a difference to creating awareness, support services and funding research.

Become a member: by joining Lung Foundation Australia, you're assisting more than six million Australians impacted by lung disease.



Appendix 1: Questions for your doctor

It may be helpful to ask your doctor about your lung cancer, so that together you can make decisions about your treatment plan. Asking your doctor questions can help you understand your condition.

Letting your doctor know your point of view will help them understand your feelings. Having someone else with you and taking notes may help you remember the information.

Some suggested questions you may want to ask your doctor include:

Diagnosis

- What type of lung cancer do I have?
- What stage is the cancer at?
- Do I need more tests?
- Do the tests have side effects?
- How soon after the tests will I learn the results?

Treatment

- What is the best treatment for me?
- Where will I go for my treatment?
- What does the treatment involve?
- Will I be in hospital? For how long?
- Will I need to travel? Who can help with this?
- How will treatment affect my usual activities?
- Are there clinical trials appropriate for my type of cancer?

Side Effects

- Should I expect any side effects?
- How long will they last?
- What side effects should I report?
- Who should I call?

Follow-up

- Who will check up on me after treatment?
- How often should I get checked?
- Should I see my doctor regularly?
- Who else can help in my community?
- Will I eventually be able to resume my normal life after treatment?

My Team

- Who will care for me?
- What do they do?
- Who will I call if I need help?
- What kind of support is available to me?

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 tube 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	Large tubes 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 millions of cells, which are adapted for different functions.
Chemotherapy	The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

Glossary

CT scan	A Computerised Tomography 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.
Enzyme	A protein that speeds up chemical reactions in the body.
Fine-needle aspiration	A biopsy procedure in which a fine needle is placed into a lump to extract cells.
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 and 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 cardiothoracic 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 tumour of the membranes around the lungs (pleura). Exposure to asbestos can cause mesothelioma.
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 carcinoma (NSCLC)	One of the two main groups of lung cancers. This group includes squamous cell carcinoma, adenocarcinoma, large cell carcinoma, bronchiolo-alveolar cell carcinoma, and mesothelioma.
Oesophagus	The tube that carries food from the throat into the stomach.
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's 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 is 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 and 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.
Protein	A molecule, made up of amino acids, which is needed for the body to function properly.
Radiotherapy	The use of ionising radiation, usually targeted x-rays or gamma rays, to kill cancer cells or injure them, so they cannot grow and multiply.
Receptor	This is a protein molecule inside or on the surface of a cell that binds to a specific molecule, such as a hormone, to cause a specific physiologic effect in the cell.



Glossary

Respiratory system	The system of the body responsible for breathing.
Resection	Surgical removal of a portion of any part of the body.
Small cell carcinoma	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 small cell lung cancer that arises in the squamous or skin-like cells of the body.
Staging	Performing tests to determine how far a 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	Also known as 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.

Lung Foundation Australia would like to thank Cancer Council for the resources they have provided in the production of this booklet.



Lung Foundation Australia extends its gratitude to the following organisations for helping to make the production of this booklet possible.



This resource is made possible through unrestricted educational grants or donations.

1800 654 301 (within Australia)

Information and Patient Support



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

Please contact Lung Foundation Australia for further information on lung disease – this is a free and confidential service. Alternatively, visit our website, which has extensive resources on lung disease, patient support groups, professional resources and other initiatives.

www.lungfoundation.com.au



The Kylie Johnston Lung Cancer Network (KJLCN) is a Lung Foundation Australia initiative that aims to empower lung cancer patients, their families and carers with reliable information, support and advocacy.

No matter where you live, you can connect with other lung cancer patients and carers by joining one of our KJLCN support groups. You will have the unique opportunity to share experiences and knowledge with others in a similar situation.

www.kjlcn.org.au

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