



Understanding Lung Cancer

A guide for people with cancer,
their families and friends

Cancer
information

For information & support, call

13 11 20



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Note to reader

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

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

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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Introduction

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

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

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

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

How this booklet was developed

The information in this booklet was developed with help from a range of health professionals and people affected by lung cancer. It is based on Australian clinical practice guidelines for lung cancer.¹

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



**Cancer
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13 11 20**

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What is cancer?

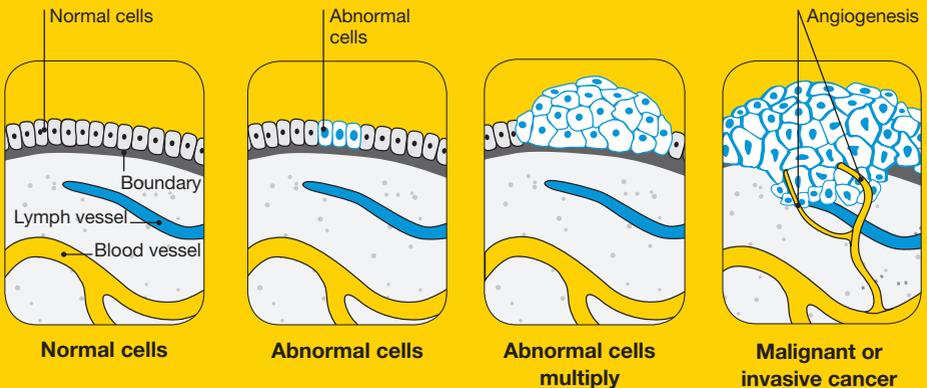
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels in a process called angiogenesis.

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, lung cancer that has spread to the bones is called metastatic lung cancer, even though the person may be experiencing symptoms caused by problems in the bones.

How cancer spreads

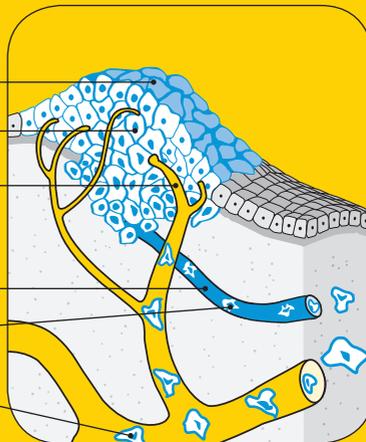
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





The lungs

The lungs are the main organs for breathing, and are part of the respiratory system. As well as the lungs, the respiratory system includes the nose, mouth, windpipe (trachea), and airways (tubes) to each lung. These consist of large airways known as bronchi (singular: bronchus) and small airways called bronchioles.

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

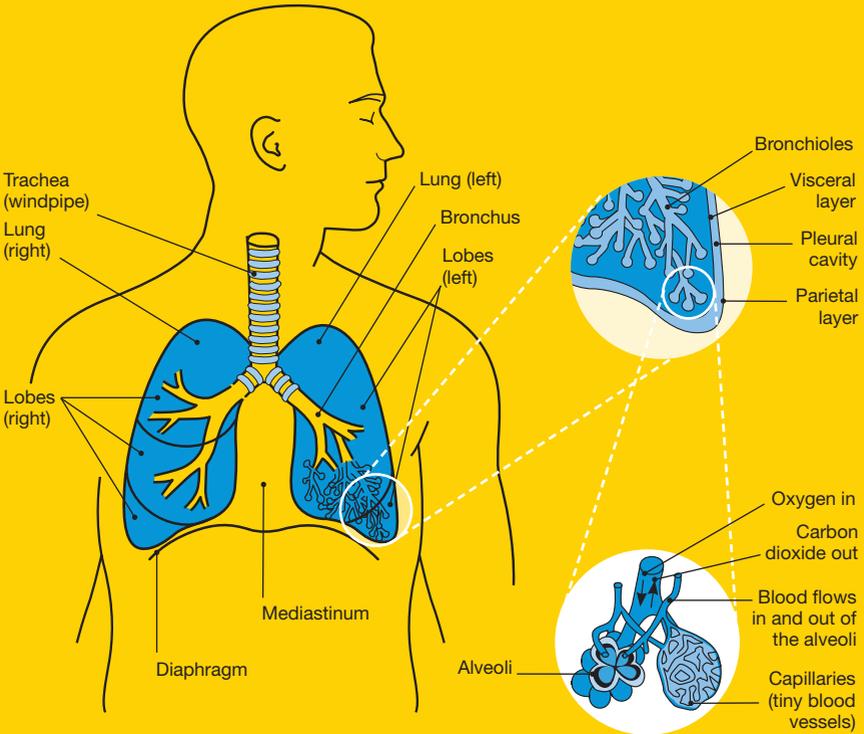
The space between the two lungs is called the mediastinum. A number of structures lie in this space, including:

- the heart and large blood vessels
- the windpipe (trachea) – the tube that carries air into lungs
- the oesophagus – the tube that carries food from the mouth to the stomach
- lymph nodes – bean-shaped structures that collect lymph fluid and foreign matter from the lungs.

The lungs are covered by two layers of a thin sheet of tissue called the pleura, which is about as thick as plastic cling wrap. The inner layer (the visceral layer) is attached to the lungs, and the outer layer (the parietal layer) lines the chest wall and diaphragm. Between the two layers is the pleural cavity (also called pleural space), which normally contains a small amount of fluid. This fluid allows the two layers of pleura to slide over each other so the lungs move smoothly against the chest wall when you breathe.

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

The respiratory system





Key questions

Q: What is lung cancer?

A: Lung cancer is a malignant tumour that grows in an uncontrolled way in one or both of the lungs.

Cancer that starts in the lungs is known as primary lung cancer. It can spread to other parts of the body such as the lymph nodes, brain, adrenal glands, liver and bones.

Sometimes a cancer starts in another part of the body and spreads to the lungs. This is known as secondary or metastatic cancer in the lung.

This booklet is about primary lung cancer only.

Q: What are the different types?

A: There are several types of primary lung cancer, which are classified according to the type of cells affected, and a number of less common subtypes. Cancers are named for the way the cells appear when viewed under a microscope.

Non-small cell lung cancer (NSCLC) – Makes up over 80% of lung cancers. NSCLC may be classified as:

- adenocarcinoma (begins in mucus-producing cells and is more often found in the outer part of the lungs)
- squamous cell carcinoma (most commonly develops in the larger airways)
- large cell undifferentiated carcinoma (the cancer cells are not clearly squamous or adenocarcinoma).

Small cell lung cancer (SCLC) – Makes up about 15–20% of lung cancers. SCLC tends to start in the middle of the lungs, and usually spreads more quickly than NSCLC.

Other tumours starting in the space between the lungs (mediastinum) or chest wall – Thymus gland tumours, germ cell tumours, tumours of nerve tissue and lymph gland tumours (lymphoma) can arise in the mediastinum. These are not strictly lung cancer. Primary tumours of bone, cartilage or muscle can also arise in the chest wall but these are rare.

Mesothelioma – A type of cancer that affects the covering of the lung (the pleura). It is different to lung cancer. There are two main types of mesothelioma: pleural and peritoneal. In most cases, exposure to asbestos is the only known cause of pleural mesothelioma. Call Cancer Council 13 11 20 for a free copy of *Understanding Pleural Mesothelioma*, or download a digital version from your local Cancer Council website.

Q: How common is lung cancer?

A: Each year, about 11,000 Australians are diagnosed with lung cancer.² The average age at diagnosis is 71. It is the fifth most common cancer in Australia and accounts for close to 9% of all cancers diagnosed.

More men than women develop lung cancer.³ The risk of being diagnosed before the age of 85 is 1 in 13 for men and 1 in 22 for women.

Q: What are the risk factors?

A: While the causes of lung cancer are not fully understood, a number of risk factors are associated with developing the disease. These include:

Tobacco smoking – Smoking causes almost 9 out of 10 lung cancers. Compared with nonsmokers, smokers are 25 times more likely to develop lung cancer.⁴ In Australia, about 84% of lung cancer cases in males, and 74% in females, are estimated to be a result of tobacco smoking.⁵

The risk of developing lung cancer is strongly linked to the age a person starts smoking, how long they smoke and the number of cigarettes they smoke.

Second-hand smoking – Breathing in other people's tobacco smoke (passive or second-hand smoke) can cause lung cancer.

People who have never smoked but who have been frequently exposed to second-hand smoke are 20–30% more likely to develop lung cancer than nonsmokers who have not been exposed. People who have never smoked and have not been around second-hand smoke have about a 0.5% risk of developing lung cancer.

Exposure to asbestos – People who are exposed to asbestos have a greater risk of developing cancer, particularly pleural mesothelioma (see previous page).

Although the use of asbestos in building materials has been banned nationally since 2003, it may still be in some older buildings. People who have been exposed to asbestos and are, or have been, a smoker are at even greater risk.

It can take many years after being exposed to asbestos for mesothelioma to develop. This is called the latency period or latent interval, and it is usually between 20 and 60 years.

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

Family history – Having a family member diagnosed with lung cancer increases the risk.

Personal history – The risk of developing lung cancer is increased if you have been previously diagnosed with another lung disease such as lung fibrosis, chronic bronchitis, emphysema or pulmonary tuberculosis.

Older age – Lung cancer is most commonly diagnosed in people aged 60 years and older, though it can occur in younger people.

If you are concerned about any of these risk factors, talk to your doctor.

Q: What are the symptoms?

A: The main symptoms of lung cancer are:

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

A person may have also experienced symptoms such as fatigue, weight loss, hoarse voice, wheezing, difficulty swallowing, and abdominal or joint pain. Lung cancer symptoms can be vague and the disease is often discovered when it is advanced (has spread to other parts of the body).

Having any one of these symptoms does not necessarily mean that you have cancer. Some of these symptoms may be caused by other conditions or from the side effects of smoking. However, if you have symptoms, see your doctor without delay.

Sometimes, there are no symptoms and the cancer is found during routine tests (often an x-ray or CT scan) for other conditions. If so, the cancer is more likely to be in an early stage of development (confined to the lungs).

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



Diagnosis

Your doctors will perform a number of tests to obtain a diagnosis, and work out whether the cancer has spread beyond the lung. This information will help your health care team develop a treatment plan.

General tests

To investigate abnormal symptoms, your doctor may arrange several imaging tests.

Chest x-ray

A chest x-ray is painless and can show tumours 1 cm wide or larger. Small tumours may not show up on an x-ray or may be hidden by other organs within the chest cavity. After a chest x-ray, you may need more detailed tests.

CT scan

A CT (computerised tomography) scan uses x-ray beams to take many pictures of the inside of your body and uses a computer to compile them into one detailed, cross-sectional picture. It can detect smaller tumours than those found by chest x-rays, and provides detailed information about the tumour, the lymph nodes in the chest and other organs.

CT scans are usually done at a hospital or a radiology clinic. You may be asked to fast (not eat or drink) for several hours before the scan to make the scan pictures clearer and easier to read. Before the scan, you will be given an injection of dye into a vein in your arm. This dye is known as the contrast and it makes the pictures

clearer. The dye may make you feel hot all over, and leave a bitter taste in your mouth, and you may feel a sudden urge to pass urine.

The CT scanner is a large, doughnut-shaped machine. You will lie flat on a table that moves in and out of the scanner. The scan itself takes 10–20 minutes, but you will also need to prepare and then wait for the scan. While a CT scan can be noisy, it is painless.



The dye used in a CT scan usually contains iodine. If you have had an allergic reaction to iodine or dyes during a previous scan, let the person performing the scan know in advance. You should also let them know if you are diabetic, have kidney disease or are pregnant.

PET scan

A PET (positron emission tomography) scan is a specialised imaging test, which is available at most major hospitals. It is used to stage lung cancer (see pages 18–19), usually after the diagnosis is confirmed.

Before the scan, a small amount of radioactive glucose solution will be injected into a vein, usually in your arm. This makes cancer cells show up brighter on the scan because they take up more of the glucose solution than normal cells do. You will be asked to sit quietly for 30–90 minutes while the glucose solution moves around your body, then you will lie on a table that moves through the scanning machine. The scan will show ‘hot spots’ that have taken up the high levels of radioactive glucose.

Lung function test (spirometry)

This test checks how well the lungs are working. It measures how much air the lungs can hold and how quickly the lungs can be filled with air and then emptied. You will be asked to take a full breath in and blow out into a machine called a spirometer.

Tests to find cancer in the lungs

Sputum cytology

A sputum cytology test examines a sample of mucus (sputum) from your lungs. Sputum is different to saliva as it contains cells that line the respiratory passages. To collect a sample, you will be asked to cough deeply and forcefully into a container. This can be done in the morning at home. The sample can be refrigerated until you take it to your doctor, who will send it to a laboratory to check under a microscope for abnormal cells.

Biopsy

If a tumour is suspected after an x-ray or CT scan, a sample of tissue will be taken to confirm whether you have lung cancer. The sample can be collected in different ways.

CT-guided core biopsy – This is used to obtain cells when the tumour is in the outer parts of the lungs. A CT scan will be used to guide the needle through your chest wall and into position. A small piece of tumour can usually be removed with the needle. A core biopsy is done in a hospital or radiology clinic. You will be observed for a few hours afterwards, as there is a small risk this procedure can damage the lung.

Bronchoscopy – A bronchoscopy allows the doctor to look inside the large airways (bronchi). A bronchoscope is passed down your nose or mouth, down your windpipe (trachea) and into the bronchi. The bronchoscope is a flexible tube with a light and lens for viewing. It may feel uncomfortable, but it shouldn't be painful. You will be given sedation to help you relax or a general anaesthetic, and the back of your throat will be sprayed with a local anaesthetic to numb it.

If the tumour is near your main respiratory tract, the cells can be collected using the washing or brushing technique. During 'washing', a small amount of fluid is injected into the lung and withdrawn for further examination. 'Brushing' involves the use of a brush-like instrument to remove some cells from the bronchi.

Endobronchial ultrasound – An endobronchial ultrasound (EBUS) is a type of bronchoscopy that allows the doctor to see cancers deeper in the lung. Samples may also be taken from a tumour or a lymph node in the middle of the chest or next to the airways. In other cases, samples can be taken from the outer parts of the lung.

The doctor will use a bronchoscope with a small ultrasound probe on the end. The ultrasound probe uses soundwaves to create pictures that show the size and position of the tumour and allow the doctor to measure it. After an EBUS, you may have a sore throat or cough up a small amount of blood. These side effects usually pass quickly, but tell your medical team how you are feeling so they can monitor you.

Mediastinoscopy – This is not used as often as other biopsy methods, but is sometimes used if a sample is needed from the area between the lungs (mediastinum). A small cut is made in the front of the neck and a rigid tube is passed down the outside of the trachea. Some tissue is removed from the mediastinal lymph nodes. A mediastinoscopy is usually a day procedure but you may need to stay overnight in hospital for observation.

Thoracoscopy – A thoracoscopy is an operation used to take a tissue sample (biopsy). It is usually done if other tests are unable to provide a diagnosis. For a thoracoscopy you will have a general anaesthetic. The surgeon will make one or two small cuts in your chest and insert a surgical instrument called a thoracoscope, which has a camera attached. You will wake up with a drain coming from your side and stay in hospital for a few days.

Gene mutation testing

Genes are found in every cell of the body and inherited from both parents. A change in genes is called a mutation, and this can cause cancer to grow. A mutation can occur after you are born.

Some genetic mutations have been identified in lung cancers. Tumour tissue

from a biopsy can be tested to find a mutation. The results help guide treatment decisions. Some medicines target particular mutations, so one option may be targeted therapy (see pages 36–38). However, not all gene mutations associated with lung cancer have a targeted therapy available.

Further tests

If the tests described on pages 13–17 show that you have lung cancer, further tests are done to see whether the cancer has spread to other parts of your body. These tests may include an abdominal CT scan (to look for liver metastases); bone scan (to look for bone metastases); and brain CT or MRI scan (to look for brain metastases). Small cell lung cancer can also spread to the bone marrow, so you may have a bone marrow biopsy to look for this.

For information about these tests, talk to your doctor or call Cancer Council 13 11 20.

Staging lung cancer

Working out how far the cancer has spread is called staging, and it helps your health care team recommend the best treatment for you.

Both NSCLC and SCLC are staged in similar ways. The most common staging system for lung cancer is the TNM system (see table opposite). TNM stands for tumour-nodes-metastasis. Each letter is assigned a number (and sometimes a or b) to show how advanced the cancer is. This information may be combined to give the lung cancer an overall stage of I, II, III or IV.

Stages I and II generally include T1–2 N0–1 M0 tumours and are usually referred to as early lung cancer. Stage III covers any T N2–3 M0 tumours and is called locally advanced lung cancer. Stage IV refers to any T and N M1 tumours that are metastatic (advanced cancer) and have spread beyond the lung and regional lymph nodes.

TNM system

The TNM system is complex. If you have any questions, ask your doctor to explain.

T (Tumour)

Indicates the size of the tumour and the depth of any tumour invasion into the lung.

- **T1a** – tumour is less than 2 cm
- **T1b** – tumour is between 2 cm and 3 cm
- **T2a** – tumour is between 3 cm and 5 cm
- **T2b** – tumour is between 5 cm and 7 cm
- **T3** – tumour is more than 7 cm or has grown into the chest wall, mediastinal pleura, diaphragm or pericardium, or it has made the lung collapse
- **T4** – tumour has grown into nearby structures, such as the mediastinum, heart, trachea, area where the main airway divides to go into each lung, oesophagus or the backbone, or two or more separate tumours are present in the same lobe of a lung

N (Nodes)

Shows if the tumour has spread to nearby lymph nodes, includes N0–3

M (Metastasis)

Shows if the tumour has spread to other parts of the body.

- **M0** – cancer has not spread to distant parts of the body
- **M1a** – separate tumour in a contralateral lobe, tumour with pleural nodules or malignant pleural effusion
- **M1b** – cancer has spread to distant parts of the body, such as the liver or bones



Lillian's story

Two days after my 34th birthday I woke up with a sore shoulder and arm. I didn't think too much of it because the pain went away quickly. After I felt a lump on my left collarbone, I mentioned it to my dad and brother because they're doctors. They said it was probably because I'd had a cough in the past weeks but to get an ultrasound.

After some further scans and tests, it was confirmed to be stage IV non-small cell lung cancer. I was devastated.

When I first tell someone that I have lung cancer, the first thing most people say is 'did you smoke?' While I think that people have the best intentions and it's human nature to want to find the cause of a problem, does it really matter whether I had smoked or not? I'm a never-smoker, but if I did smoke, even if it was just one cigarette, should I feel that somehow it's my fault?

I want to reduce the stigma suffered by lung cancer patients and their families who are already going through so much. I use statistics to educate people and raise awareness. I explain that many other lifestyle choices are linked to cancer and that smoking causes other health conditions, such as cardiovascular diseases and other cancers. I let them know that one in three women diagnosed with lung cancer is a never-smoker such as myself.

A lot of the people I've met with lung cancer, say they're guarded about their diagnosis. One carer said she didn't tell anyone for three years that her spouse had lung cancer for fear of being stigmatised. There needs to be a lot more compassion. I think that taking away the stigma will lead to greater funding for research. I am feeling hopeful about my future. It's important to me to stay in the moment and appreciate what I have.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease. Instead, your doctor can give you an idea about the general prognosis for people with the same type and stage of cancer.

As in most types of cancer, the results of lung cancer treatment tend to be better when the cancer is found and treated early. See pages 18–19 for more information about staging lung cancer.



To work out your prognosis, your doctor will consider your test results; the type of lung cancer; the rate and extent of tumour growth; how well you respond to treatment; and other factors such as your age, fitness and overall health, and whether you're currently a smoker.

Which health professionals will I see?

Your general practitioner (GP) will usually arrange the first tests to assess your symptoms. If these tests don't rule out cancer, you'll usually be referred to a respiratory physician, who will arrange further tests and advise you about treatment options.

A range of health professionals will work as a multidisciplinary team (MDT) to treat you. The table on the next page lists the health professionals who may be in your MDT. The health professionals you see will depend on whether you have early stage lung cancer or more advanced lung cancer.

Health professional	Role
respiratory physician* (thoracic physician)	diagnoses and stages the cancer and determines initial treatment options
thoracic (chest) surgeon*	conducts some diagnostic tests and performs surgery for lung cancer
radiation oncologist*	prescribes and coordinates the course of radiotherapy
radiation therapist	plans and delivers radiotherapy and provides care throughout treatment
medical oncologist*	prescribes and coordinates the course of chemotherapy and targeted therapy
oncology nurses	administer drugs, including chemotherapy, and provide care throughout treatment
cancer nurse coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment
dietitian	recommends an eating plan to follow during treatment and recovery
speech pathologist	helps with communication and swallowing
social worker	links you to support services and helps with emotional or practical problems
physiotherapist, occupational therapist	assist with physical and practical issues
counsellor, psychologist	provide emotional support and help manage anxiety and depression
palliative care team	specialise in pain and symptom control to maximise wellbeing and improve quality of life

* Specialist doctor



Key points

- Several tests may be performed to diagnose lung cancer. These include general tests and tests to determine whether the cancer has spread.
- Chest x-rays and CT scans are painless scans that will take pictures of the inside of your body.
- If you are coughing up phlegm, your doctor might ask you for a sample to send to a lab for testing. This is called sputum cytology.
- A biopsy is when a sample of tissue is removed from your chest. The sample can be collected in different ways, including CT-guided core biopsy, bronchoscopy, endobronchial ultrasound (EBUS), mediastinoscopy and thoracoscopy.
- Some genetic mutations have been identified in lung cancers. Tumour tissue can be tested to find a mutation. The results can help guide treatment options.
- Scans and biopsy results can show whether the cancer has spread. They can also help your medical team decide on the best treatment plan.
- The lung cancer is assigned a stage to describe how much cancer there is and whether it has spread.
- Prognosis is the expected outcome of the disease. No-one can predict the exact course of the illness.
- A range of health professionals who specialise in different areas will work together to care for you. This multidisciplinary team (MDT) may include a respiratory physician, thoracic surgeon, radiation oncologist and a medical oncologist.



Making treatment decisions

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

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

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

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask your doctor questions – see page 51 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

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

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

Taking part in a clinical trial

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

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

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



Treatment for early lung cancer

Treatment for lung cancer will depend on the type of lung cancer you have, the stage of the cancer, your breathing capacity and your general health. NSCLC and SCLC are treated in different ways.

Treatment options by type and stage

Non-small cell lung cancer (NSCLC)

Early stage – Usually treated with surgery, including removal of nearby lymph nodes. If surgery is not an option, radiotherapy is offered. Sometimes, chemotherapy may be given after surgery or with radiotherapy.

Locally advanced – Stage III cancer can be treated with surgery and chemotherapy or with radiotherapy and chemotherapy. Treatment will depend on the number and location of lymph nodes with cancer.

Advanced – Palliative chemotherapy and/or palliative radiotherapy may be offered depending on symptoms. New targeted therapy drugs may also be an option.

Small cell lung cancer (SCLC)

Stages I–III – Chemotherapy and radiotherapy are the main treatments. Surgery is not used.

Stage IV – Palliative chemotherapy is the main treatment. Palliative radiotherapy may also be given to the brain, spine, bone or other parts of the body where the cancer has spread.

Surgery

People with early stage NSCLC (stage I and stage II) will generally have surgery to remove the tumour. How much of the lung is removed depends on the location of the cancer, its size, your general wellbeing and fitness, as well as your lung function. See the next page for an illustration of the types of surgery.

Removing lymph nodes

During surgery, nearby lymph nodes will also be removed to see whether the cancer has spread. Knowing if the cancer has spread to the lymph nodes also helps the doctors decide whether you need further treatment with chemotherapy or radiotherapy.

How the surgery is done

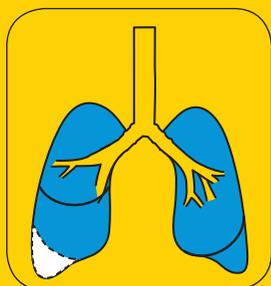
The surgery can be done in different ways. If a cut is made between the ribs in the side of the chest, the operation is called a thoracotomy. You will need to stay in hospital for 3–7 days.

It's becoming more common for surgery to be done with a keyhole approach. This is known as video-assisted thoracoscopic surgery (VATS). It involves making three to four cuts in the chest wall, known as ports, and inserting a small video camera and operating instruments that allow the surgeon to perform the operation from outside the chest. A keyhole approach usually means a shorter hospital stay, faster recovery and fewer side effects.

Call Cancer Council 13 11 20 for more information or a copy of the *Understanding Surgery* booklet, or download a digital version from your local Cancer Council website.

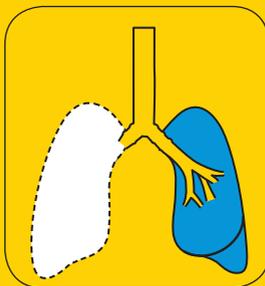
Types of lung surgery

There are several types of lung surgery.



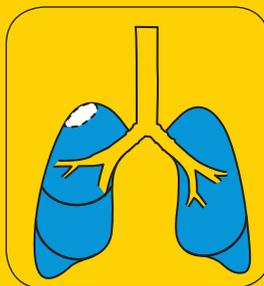
Lobectomy

A lobe of the lung is removed.



Pneumonectomy

One whole lung is removed.



Wedge resection

Only part of the lobe is removed.

What to expect before surgery

If you smoke, your medical team will advise you to stop before you have surgery. If you continue to smoke during treatment, you may not respond to treatment as well as people who don't smoke. Also, the side effects may be worse. See your doctor or call the Quitline on 13 7848 (13 QUIT) to find out about quitting products.

What to expect after surgery

Tubes and drips – You will have several tubes in place, which will be removed as you recover. A drip inserted into a vein in your arm (intravenous drip) will give you fluid, medicines and pain relief. There may be one or two temporary tubes in your chest to drain fluid and/or air from your chest cavity.

Pain – This is common after surgery, but can be controlled. Managing the pain will help you to recover and move around more quickly, and allow you to do your breathing exercises. Pain relief may also help clear phlegm from your chest.

Recovery time – You will probably go home 3–7 days after the operation. It may take 6–12 weeks to resume your usual routine and activities. The recovery time depends on the type of surgery and your fitness. Your doctor, nurses and physiotherapist will talk to you about how to manage at home. Walking will improve your fitness, clear your lungs and speed up recovery.

Breathlessness – This is common if you've had part of your lung removed, especially if your lung function was poor before surgery, or if you have had a whole lung removed (pneumonectomy). Gentle exercises as part of a pulmonary rehabilitation program will help improve breathlessness and reduce the risk of developing a chest infection. To find a pulmonary rehabilitation program, ask your surgeon for details or visit lungfoundation.com.au.

Thermal ablation

Ablation treatment may be offered for localised lung cancer when surgery or radiotherapy are considered unsuitable. This involves inserting needles or probes into the cancer to destroy the cancer cells by heating them. Only one treatment is needed. A CT scan is used to guide the needle into the right position. Thermal ablation is not painful, but you may have a general anaesthetic to make you more comfortable during the procedure.

Radiotherapy

Radiotherapy uses x-rays to kill or damage cancer cells. It can be used to treat all types of lung cancer. It may be offered on its own or in combination with surgery or chemotherapy.

Radiotherapy can be used:

- to treat an early stage lung cancer if you are unable to have surgery
- to treat locally advanced (stage III) NSCLC or stages I–III SCLC
- after surgery if the mediastinal lymph nodes contained cancer, to reduce the risk of the cancer coming back in the mediastinum
- as palliative treatment to treat cancer that has spread to other organs, such as the brain or bones, and is causing symptoms
- as palliative treatment to relieve pain and improve quality of life or extend your life (see page 39).

Before treatment starts, the radiation oncology team will plan your treatment, and will explain the treatment schedule and the possible side effects. These are briefly described on page 32.

During treatment, you will lie on an examination table, and a radiotherapy machine will be aimed at the chest area. The radiation therapist will place you and the machine in the correct position and then leave the room. You will not feel anything during the treatment, but may hear a buzzing sound from the machine. The treatment itself takes only a few minutes, but the full session may last for about 10–20 minutes.

For more information about radiotherapy and its side effects, talk to your doctor and nurses, or call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*, or download a digital version from your local Cancer Council website.

Types of external radiotherapy

Radiotherapy may be delivered in different ways depending on the type of lung cancer. It is usually given as daily treatment over a number of weeks. Palliative radiotherapy usually involves 1–10 treatments. A course of curative radiotherapy usually involves between 20–33 treatments over 4–6 weeks. Treatment is generally given during the weekdays with a rest over the weekend.

Stereotactic ablative body radiotherapy (SABR) –

This is a way of giving highly focused radiotherapy to small NSCLC tumours while the surrounding tissue receives a low dose. SABR is delivered from multiple beams that meet at the tumour. You may have 1–5 treatment sessions, 1–2 days apart for a couple of weeks. SABR is only suitable for tumours not close to major airways, blood vessels or the spinal cord.

Hyperfractionated radiotherapy –

This means having more than one treatment of radiotherapy a day. Each treatment will be at least six hours apart to allow time for the healthy cells to repair themselves.

The whole dose of radiation is about the same as you would have for standard radiotherapy. This form of treatment is usually considered for SCLC.

Side effects of radiotherapy

The side effects of radiotherapy vary depending on the dose of radiation and the number of treatments.

Difficulty swallowing and heartburn – This may occur during treatment and continue for up to 3–4 weeks after treatment ends. You may need to change to a soft food diet and avoid hot drinks, such as tea and coffee, until these side effects improve.

Skin changes – The skin on your chest and back may become red or dry, like sunburn. Moisturising cream, such as sorbolene, should be applied to the skin when treatment starts – talk to your medical team about other products they recommend.

Fatigue – Feeling tired is common after radiotherapy. Plan your daily activities so you can rest regularly. It may also help to talk to your family, friends or employer about how they can help you.

Shortness of breath and cough – Radiotherapy may cause inflammation of the lungs, known as radiation pneumonitis. This may cause shortness of breath or a cough, sometimes during treatment but more likely one to six months after treatment ends. Radiation pneumonitis is usually temporary and can be treated with steroid (cortisone) tablets.

Side effects can change from one period of radiotherapy to the next and may build up over time. Let the radiation oncologist, radiation therapist or nurse know of any side effects you experience, as they can usually be managed.

Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. The aim is to destroy cancer cells while causing the least possible damage to normal, healthy cells. Chemotherapy can be used at different times, including:

- before surgery (neo-adjuvant chemotherapy), to try to shrink the cancer and make the operation easier
- before radiotherapy or during radiotherapy (chemoradiotherapy or chemoradiation), to make radiotherapy more effective
- after surgery (adjuvant chemotherapy), to reduce the risk of the cancer returning
- as palliative treatment, to reduce symptoms, improve your quality of life or extend your life (see page 39).

Chemotherapy is usually delivered through an intravenous drip. Each chemotherapy treatment is called a cycle and is followed by a rest period to give your body time to recover. The number of treatments you have will depend on the type of lung cancer you have and how well your body is coping with the side effects. You will probably have chemotherapy as an outpatient, which means you won't have to stay in hospital overnight. Ask your doctor about the treatment plan recommended for you.

Some types of chemotherapy can be taken by mouth (orally) in tablet form, and are generally used on a continuous basis.

To find out more, call Cancer Council 13 11 20 for a free copy of the booklet *Understanding Chemotherapy*, or download a digital version from your local Cancer Council website.

Side effects of chemotherapy

Chemotherapy can affect the healthy cells in the body and cause side effects. Everyone reacts differently to chemotherapy, and effects will vary according to the drugs you are given. Often side effects are temporary. Talk to your medical team about what to expect.

Anaemia – A low red blood cell count is called anaemia. This can make you feel tired or breathless. Your treatment team will monitor your red blood cell levels and suggest treatment if necessary.

Risk of infections – Chemotherapy drugs lower the number of white blood cells that fight infections. This can make you more likely to develop colds or the flu. If you feel unwell or have a temperature higher than 38°C, call your doctor immediately or go to the hospital emergency department.

Mouth ulcers – Some chemotherapy drugs cause mouth sores, ulcers or thickened saliva, which make it difficult to swallow. For more detailed information, call Cancer Council 13 11 20 for a free copy of the *Mouth Health and Cancer Treatment* fact sheet, or download it from your local Cancer Council website.

Hair loss – You may lose hair from your head and chest, depending on the chemotherapy drugs you receive. The hair will grow back after treatment is completed, but the colour and texture may change.

Nausea or vomiting – It is common to feel sick (nauseated) or vomit. Let your treatment team know if you feel nauseated.



Key points

- Treatment will depend on the type of cancer, its stage, and your general fitness and suitability for the treatment.
- If you have surgery, you may have a whole lung, a lobe or part of a lobe removed. If you are a smoker, you will be encouraged to stop smoking before surgery.
- Effective pain management, gentle breathing exercises as part of a pulmonary rehabilitation program, and being active will help your recovery after surgery.
- Radiotherapy uses radiation such as x-rays to damage or kill cancer cells. It can be used to treat all types of lung cancer. It may be offered on its own or together with surgery or chemotherapy. Side effects may include difficulty swallowing and heartburn, red or dry skin, or shortness of breath or cough.
- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. Most chemotherapy drugs can cause side effects such as anaemia, risk of infections, mouth ulcers, hair loss and nausea or vomiting.
- If the cancer has spread outside the lung and to other parts of the body, this is considered advanced lung cancer. The goal of treatment is to slow the spread and manage symptoms.
- Treatment to target specific mutations within cancer cells is called targeted therapy. Some targeted therapy drugs may be available only through a clinical trial.
- Palliative treatment aims to improve people's quality of life by relieving symptoms of cancer without trying to cure the disease. It is part of palliative care.



Treatment for advanced lung cancer

When lung cancer has spread outside the lung and to other parts of the body, the goal of treatment is to control the cancer, to slow down its spread and to manage any symptoms. Because the symptoms of lung cancer are often vague in its early stages, some people find that the cancer is advanced when it is first diagnosed.

You may have the same treatments used for treating early lung cancer, such as radiotherapy (see pages 30–32) and chemotherapy (see pages 33–34), or targeted therapy and immunotherapy. Some of these treatments may be part of palliative treatment. Specific treatments to manage symptoms that make breathing difficult are covered in the *Managing symptoms* chapter (see pages 40–42).

Targeted therapy

New types of drugs known as targeted therapy or personalised medicine target specific mutations within cancer cells and often work by blocking cell growth. Targeted therapy drugs are generally used for advanced NSCLC (stage IV) or if the cancer has come back (recurred). Clinical trials are studying whether targeted therapy is helpful in treating small cell lung cancer.

Different types of targeted therapy drugs are used for advanced lung cancer (see box, next page).

Cancer cells often become resistant to targeted therapy drugs over time. If this first-line treatment stops working, your doctor will suggest trying another targeted therapy drug. This is known as second-line treatment.

Targeted therapy is available for two common gene mutations associated with lung cancer: epidermal growth factor receptor (EGFR) and anaplastic lymphoma kinase (ALK) mutations.

Some targeted therapy drugs approved for lung cancer include:

- EGFR – erlotinib, afatinib and gefitinib
- ALK – crizotinib, ceritinib and alectinib.

Some targeted therapy drugs may be available only through a clinical trial (see page 25). This area of science is changing rapidly, and it's likely that new mutations and targeted therapy drugs will continue to be discovered. Talk to your doctor for more information about new drug trials.

Types of targeted therapy

In Australia, there are currently two main types of targeted therapy used to treat lung cancer: monoclonal antibodies and small molecule inhibitors.

Monoclonal antibodies	Small molecule inhibitors
<ul style="list-style-type: none"> • stop the cancer developing new blood vessels and growing • usually given intravenously • the drug bevacizumab is given with chemotherapy every 3 weeks 	<ul style="list-style-type: none"> • stop cancer cells growing and multiplying • usually given as tablets • the drugs erlotinib and gefitinib are used for NSCLC with EGFR mutation • the drug crizotinib is used for NSCLC with ALK mutation

Side effects of targeted therapy

Although targeted therapy drugs cause fewer side effects compared with standard chemotherapy drugs, they can still have side effects.

These vary depending on the targeted therapy drugs used, but may include an acne-like rash or other skin changes, diarrhoea, and nausea and vomiting. It's important to discuss any side effects with your medical team.

Immunotherapy

These drugs can stimulate the body's own immune system to attack the cancer. Immunotherapy may be effective in treating some forms of NSCLC such as squamous cell lung cancer.

Nivolumab and pembrolizumab are two immunotherapy drugs that work by permitting the immune system to bypass 'checkpoints' set up by the cancer that block the immune system. Both of these drugs block a protein called PD-1 found on immune cells. Nivolumab and pembrolizumab release this brake, allowing the immune system to attack cancer harder. Several checkpoint immunotherapy drugs are currently being tested in clinical trials for lung cancer.

Side effects of immunotherapy

The side effects of immunotherapy drugs are different to chemotherapy. They will vary depending on the organ affected, but may include shortness of breath (lungs) and diarrhoea (bowel).

Palliative treatment

If the cancer is advanced when it is first diagnosed or returns after treatment, your doctor will discuss palliative treatment for symptoms caused by the cancer, such as pain or breathlessness.

Palliative treatment aims to manage symptoms without trying to cure the disease. It can be used at any stage of advanced lung cancer to improve quality of life. It is not just for people who are about to die and does not mean giving up hope. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. The treatment may include chemotherapy, radiotherapy and targeted therapy. If you are experiencing fluid build-up, you may have a procedure called thoracentesis or pleural tap to drain the extra fluid from the area between the lung and the chest wall (pleural space). See the *Managing symptoms* chapter (pages 40–42) for more details.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. For more information, visit your local Cancer Council website or call 13 11 20 for free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*.



Managing symptoms

For many people, lung cancer is diagnosed at an advanced stage. The main goal of treatment is to manage your symptoms and keep them under control for as long as possible. Treatment can help you feel better and improve quality of life. This is called palliative treatment (see page 39).

Shortness of breath (breathlessness)

Many people with lung cancer have difficulty breathing (dyspnoea) and shortness of breath. This can be challenging and may cause distress. There are surgical ways to reduce its impact on your life.

Thoracentesis (pleural tap)

For some people, fluid may build up in the space between the two layers of thin tissue covering the lung (pleural cavity). This is called pleural effusion and may make it hard to breath. A procedure called thoracentesis or pleural tap can relieve this symptom.

To drain the fluid, your doctor or radiologist numbs the area with a local anaesthetic and inserts a hollow needle between your ribs into the pleural cavity. This will take about 30–60 minutes. You don't usually have to stay overnight after a thoracentesis. A sample of the fluid is sent to a laboratory for testing.

Pleurodesis

Pleurodesis means closing the pleural cavity. This may be required if the fluid accumulates again after you have had a thoracentesis. It is usually done with a type of keyhole surgery called video-assisted thoracoscopic surgery (VATS).

During the VATS, a thin instrument with a light is inserted into the pleural cavity and some sterile talcum powder is injected into the space. This causes inflammation that closes the pleural cavity and prevents fluid from building up again. Pleurodesis is usually performed under a general anaesthetic by a thoracic surgeon and requires a hospital stay of two or three days. If you are unable to have a general anaesthetic, this procedure can be performed by a doctor under local anaesthetic.

Indwelling pleural catheter

An indwelling pleural catheter is a small tube used to drain fluid from around the lungs. It may be offered to people who repeatedly experience a build-up of fluid in the pleural cavity that makes it hard to breathe.

The surgeon inserts the catheter through the chest wall into the pleural cavity. One end of the tube remains inside the chest, and a small length remains outside the body for drainage. This end is coiled and tucked under a small dressing. The pleural catheter is connected to a small bottle to remove fluid and help you breathe.

You may have to drain the fluid 1–2 times a week depending on how quickly it builds up again. You can manage the catheter at home with the help of a community nurse. Your family or a friend can also be taught how to clear the drain.

Ask your health care team for assistance obtaining any equipment than may help, such as an oxygen concentrator.



Fatigue

It is common to feel very tired during or after treatment and you may lack the energy to carry out day-to-day activities. Fatigue for people with cancer is different from tiredness, as it doesn't always go away with rest or sleep.

If fatigue continues for long periods of time, you may lose interest in things that you usually enjoy doing or feel unable to concentrate on one thing for very long. Let your treatment team know if you are struggling with fatigue. Sometimes fatigue can be caused by a low red blood cell count or the side effects of drugs, and can be treated.

Poor appetite and weight loss

For many people, losing weight and interest in eating are common. These symptoms may be caused by nausea, difficulty swallowing, breathlessness, or feeling down (see page 45).

Maintaining good nutrition will help you cope better with day-to-day living, treatment and side effects, and improve your quality of life. You may find it useful to talk to a dietitian who is experienced in treating people with cancer.



Looking after yourself

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

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet, or download a digital version from your local Cancer Council website.

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

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

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or download it from your local Cancer Council website.

Sexuality, intimacy and fertility

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

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



Call **13 11 20** for free copies of *Sexuality, Intimacy and Cancer* and *Fertility and Cancer*, or download the booklets from your local Cancer Council website.

Relationships with others

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

Life after treatment

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

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

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

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, specialist or nurse as counselling or medication – even for a short

time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to beyondblue.org.au or call **1300 22 4636** to order a fact sheet.

Follow-up appointments

After your treatment, you will need regular check-ups. Your check-ups may include chest x-rays, CT scans and blood tests.

Follow-up appointments may be every 3–6 months for the first couple of years and 6–12 months for the following three years. If you have received more than one type of treatment, you may have appointments with different specialists. Between appointments, let your doctor know immediately of any health problems.

What if the cancer returns?

For some people, lung cancer does come back after treatment, which is known as a recurrence. Lung cancer is more likely to recur in the first five years following diagnosis. This is why it is important to have regular check-ups.

If the cancer recurs, your doctor will discuss your treatment options with you. These will depend on the type of lung cancer and where the cancer has recurred, as well as the stage and grade of the cancer. It may also be necessary to have another biopsy to check for gene mutations. You may be offered the following:

- **recurrent non-small cell lung cancer** – radiotherapy, chemotherapy, targeted therapy, or the option to join a clinical trial
- **recurrent small cell lung cancer** – chemotherapy, radiotherapy or the option to participate in a clinical trial.



Seeking support

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

Practical and financial help

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

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

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

Talk to someone who's been there

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

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

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

Types of support

There are many ways to connect with others for mutual support and to share information. These include:

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

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” *Sam*



Caring for someone with cancer

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

Many cancer support groups and cancer education programs are open to carers. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

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

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit carersaustralia.com.au or phone 1800 242 636 for more details. You can call Cancer Council 13 11 20 to find out more about carers' services and support groups and to get a copy of the *Caring for Someone with Cancer* booklet.

Lung Cancer: Understanding, Managing, Living is a DVD available from Lung Foundation Australia. Visit lungcancernetwork.com.au, or call **1800 654 301** to request a free copy.





Useful websites

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

Australian

Cancer Council Australia.....	cancer.org.au
Cancer Australia.....	canceraustralia.gov.au
Carer Gateway.....	carergateway.gov.au
Carers Australia.....	carersaustralia.com.au
Department of Health.....	health.gov.au
Healthdirect.....	healthdirect.gov.au
beyondblue.....	beyondblue.org.au
Quit Now.....	quitnow.gov.au

Lung cancer-specific

Lung Cancer Network Australia.....	lungcancernetwork.com.au
Lung Foundation Australia.....	lungfoundation.com.au

International

American Cancer Society.....	cancer.org
Macmillan Cancer Support (UK).....	macmillan.org.uk
National Cancer Institute (US).....	cancer.gov
Mesothelioma Center (US).....	asbestos.com



Question checklist

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

- What type of lung cancer do I have?
- Has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- 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? Will I have to stay in hospital?
- How much will treatment cost?
- Will the treatment cause any pain? How will the pain be managed?
- Are the latest tests and treatments for lung cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my follow-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- How will I know if the cancer comes back?
- If the cancer comes back, what are my treatment options?



Glossary

ablation

Inserting needles or probes into the cancer to destroy cancer cells with heat.

adenocarcinoma

A cancer that starts in the mucus-producing cells that form part of the lining of the internal organs.

advanced cancer

Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

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 temporary loss of consciousness.

asbestos

A naturally occurring silicate mineral that forms long, crystallised fibres. Now banned in Australia because the fibres can cause serious illness.

benign

Not cancerous or malignant.

biopsy

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

bronchioles

The smallest airways (tubes) that carry air into the outer parts of the lungs.

bronchoscopy

A test to examine the lungs and respiratory system.

bronchus (plural: bronchi)

The large airway or tube that carries air into the lungs.

capillary

The smallest blood vessels in the body.

catheter

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

cells

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

chemoradiotherapy (chemoradiation)

Combined chemotherapy and radiotherapy treatment.

chemotherapy

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

core biopsy

A type of biopsy where a tissue sample is removed with a wide needle for examination under a microscope.

CT scan

Computerised tomography scan. This scan uses x-rays to create a picture of the inside 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 non-cancerous condition in which

the alveoli of the lungs are enlarged and damaged, usually due to smoking. It causes breathing difficulties.

endobronchial ultrasound (EBUS)

A type of bronchoscopy that puts a flexible tube through the airways and trachea to examine the airways (bronchi) and take tissue samples.

genes

The microscopic units that determine how the body's cells grow and behave.

immunotherapy

Treatment that stimulates the body's immune system to fight cancer.

intravenous (IV)

Injected into a vein.

large cell undifferentiated carcinoma

Cancer cells are not clearly squamous cell carcinoma or adenocarcinoma.

lobe

A section of an organ. The left lung has two lobes and the right lung has three lobes.

lobectomy

An operation to remove a lobe of a lung.

lungs

The two spongy organs in the chest, made up of sections called lobes. The lungs are used for breathing, and are part of the respiratory system.

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.

lymph nodes

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

malignant

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

mediastinoscopy

A surgical procedure for examining the lymph nodes at the centre of the chest and removing 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

Cancer that affects the protective covering of the lungs (pleura).

metastasis (plural: metastases)

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

monoclonal antibodies

A type of targeted therapy that stops the cancer developing new blood vessels and growing.

MRI scan

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

mutation

A change in a gene causing a permanent change in the DNA sequence that makes up a gene.

non-small cell lung cancer (NSCLC)

One of the two main types of lung cancers. Includes squamous cell carcinoma, adenocarcinoma and large cell undifferentiated carcinoma.

oesophagus

The tube that carries food from the throat into the stomach.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other symptoms. It is an important part of palliative care.

parietal layer

The outer layer of the pleura that lines the chest wall.

PET scan

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

pleura

The thin sheet of tissue that lines the chest wall and covers the lungs. It has two layers: visceral and parietal.

pleural cavity (pleural space)

The space between the two layers of the pleura, which normally contains a small amount of fluid.

pleural effusion

A collection of fluid between the two sheets of tissue that cover the lungs.

pleural tap

See thoracentesis.

pleurodesis

An injection of sterile talcum powder

into the pleural cavity. This causes inflammation that closes the space 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 predicted outcome of a person's disease.

pulmonary

Relating to the lungs.

radiotherapy

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

small cell lung cancer (SCLC)

One of the two main types of lung cancers. It tends to spread early.

small molecule inhibitors

A type of targeted therapy that stops cancer cells growing and multiplying.

sputum

Liquid coughed up from the lungs.

Also known as phlegm.

sputum cytology test

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

squamous cell carcinoma (SCC)

A cancer that develops from squamous cells, which are flat cells found on the surface of the skin or in the lining of certain organs, such as the lungs.

staging

Performing tests to determine how far a cancer has spread.

targeted therapy

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

thoracentesis

A procedure in which a hollow needle is inserted between the ribs to drain excess fluid. Also called a pleural tap.

thoracotomy

Surgery in which a long cut is made in the chest to examine, biopsy and/or remove a tumour.

trachea

The windpipe. The trachea is the airway that brings inhaled air 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 (not cancer) or malignant (cancer).

video-assisted thoracoscopic surgery (VATS)

A surgical procedure where a cut is made in the chest, and a small video camera with a telescope called a thoracoscope is inserted.

visceral layer

The inner layer of the pleura that is attached to the lungs.

wedge resection

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

Can't find a word here?

For more cancer-related words, visit:

- cancer council.com.au/words
- cancer vic.org.au/glossary
- cancer sa.org.au/glossary

References

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How you can help

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

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

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

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

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

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

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



Cancer Council 13 11 20

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

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

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

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

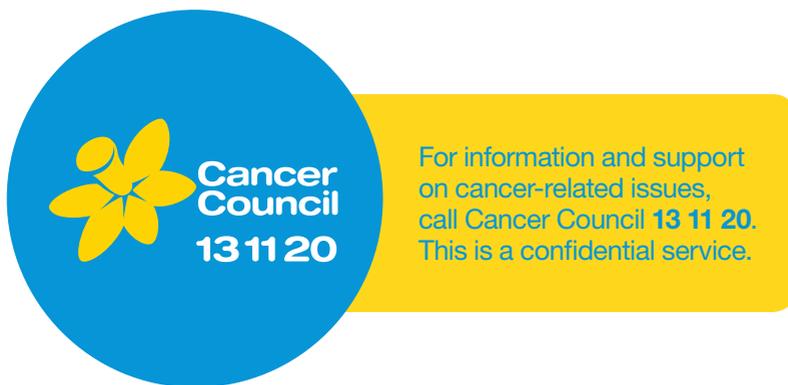
Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



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



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