



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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Understanding Lung Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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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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About this booklet

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, this information may answer some of your questions and help you think about what to ask your treatment team (see page 59 for a question checklist).

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 (see pages 60–63). You may like to pass this booklet to family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by lung cancer. It is based on Australian and international clinical practice guidelines for lung cancer.¹⁻³

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. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

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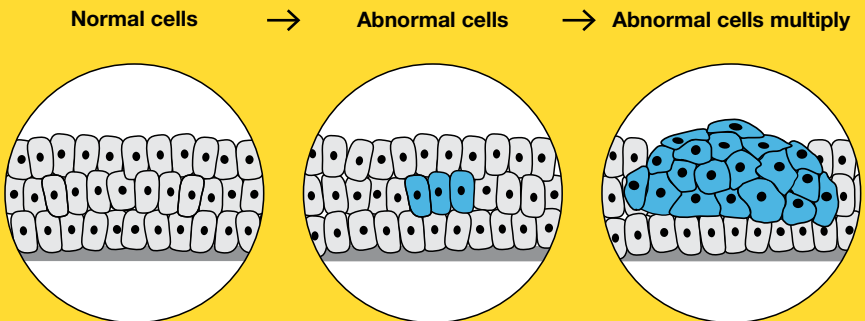
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as lung cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

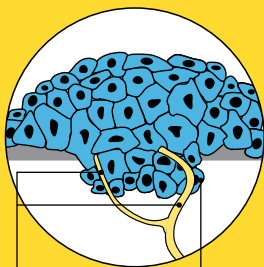
How cancer starts



cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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 main symptoms may be coming from the bones.

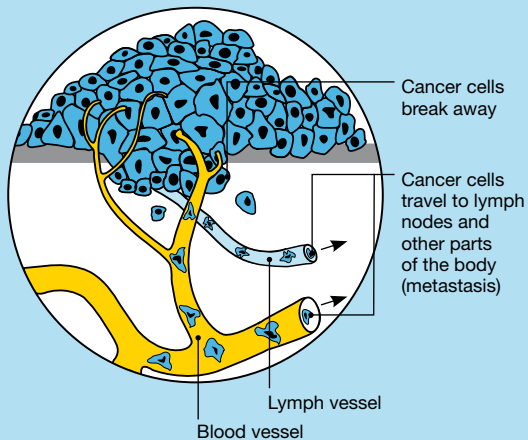
→ **Malignant cancer**



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue

How cancer spreads



Cancer cells
break away

Cancer cells
travel to lymph
nodes and
other parts
of the body
(metastasis)

Lymph vessel

Blood vessel



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, trachea (windpipe) and airways (tubes) to each lung. There are large airways known as bronchi (singular: bronchus) and small airways called bronchioles.

Lobes – The lungs are two large, spongy organs. Each lung is made up of sections called lobes – the left lung has two lobes and the right lung has three.

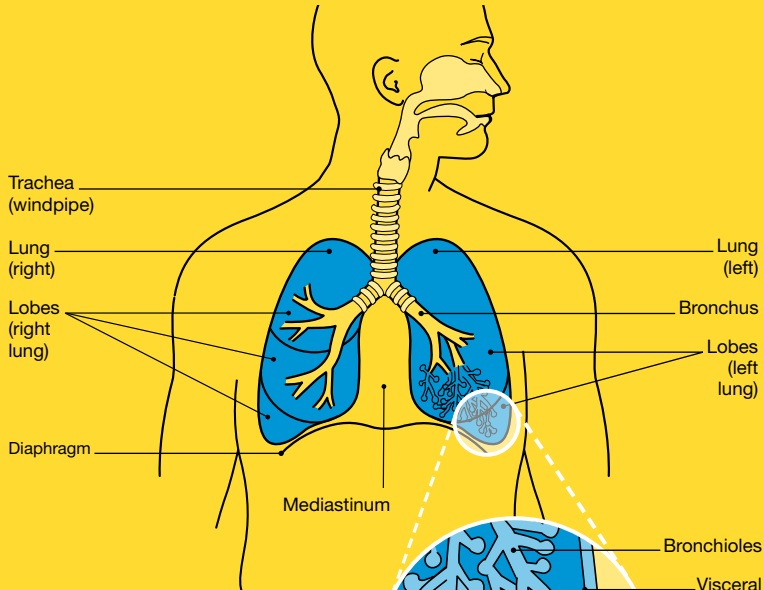
Diaphragm – The lungs rest on the diaphragm, which is a wide, thin muscle that helps with breathing.

Mediastinum – The space between the two lungs is called the mediastinum. Several structures lie in this space, including:

- the heart and large blood vessels
- the trachea – the tube that carries air into the lungs
- the oesophagus – the tube that carries food to the stomach
- lymph nodes – small, bean-shaped structures that collect and destroy bacteria and viruses.

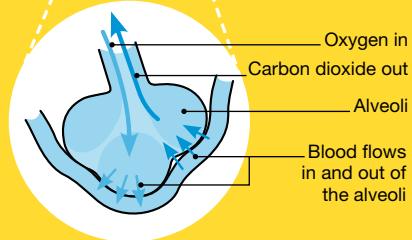
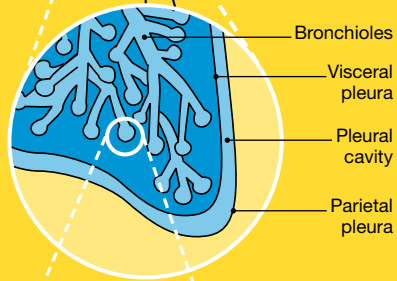
Pleura – The lungs are covered by two layers of a thin sheet of tissue called the pleura, which is about as thick as plastic cling wrap. The inner layer (the visceral pleura) lines the lung surface and the outer layer (the parietal pleura) lines the chest wall and diaphragm. The layers are separated by a film of fluid that lets them slide over each other. This fluid helps the lungs move smoothly against the chest wall when you breathe. The pleural cavity is the potential space between the two layers, but there is no space between them when the lungs are healthy.

The respiratory system



How breathing works

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 are surrounded by small blood vessels (capillaries). Inhaled oxygen passes through the alveoli into the blood, while the waste gas (carbon dioxide) moves from the blood into the alveoli. When you breathe out (exhale), carbon dioxide is removed from the body and released back into the air.





Key questions

Q: What is lung cancer?

A: Lung cancer begins when abnormal cells grow and multiply in an uncontrolled way in the lungs. Cancer that starts in the lungs is known as primary lung cancer. It can spread to the lymph nodes, brain, adrenal glands, liver and bones.

When cancer starts in another part of the body and spreads to the lungs, it is called secondary or metastatic cancer in the lung. This booklet is about primary lung cancer only.

Q: What are the different types?

A: There are two main types of primary lung cancer. These are classified according to the type of cells affected.

Types of lung cancer

non-small cell lung cancer (NSCLC)

NSCLC makes up about 85% of lung cancers. It may be classified as:

- **adenocarcinoma** – begins in mucus-producing cells; more often found in outer part of the lungs
- **squamous cell carcinoma** – begins in thin, flat cells; most often found in larger airways
- **large cell undifferentiated carcinoma** – the cancer cells are not clearly squamous or adenocarcinoma.

small cell lung cancer (SCLC)

SCLC makes up about 15% of lung cancers. It tends to start in the middle of the lungs and usually spreads more quickly than NSCLC.

Other types of cancer can also affect the lung area, but are not considered lung cancer. These include tumours that start in the space between the lungs (mediastinum) or in the chest wall.

Pleural mesothelioma is a cancer that affects the covering of the lung (the pleura). It is different from lung cancer and is usually caused by exposure to asbestos.

➤ See our *Understanding Mesothelioma* booklet.

Q: What are the risk factors?

A: The causes of lung cancer are not fully understood, and some people develop lung cancer without having any known risk factors. The factors listed below are known to increase the risk of developing the disease. Having these risk factors does not mean you will develop lung cancer, but if you are concerned about your risk, talk to your doctor.

Tobacco smoking – In Australia, about 90% of lung cancer cases in men and 65% in women are estimated to be a result of smoking tobacco. The earlier a person starts smoking, the longer they smoke and the more cigarettes they smoke, the higher the risk of developing lung cancer. However, about 1 in 5 people (21%) who are diagnosed with lung cancer have never been smokers.

Second-hand smoking – Breathing in other people's tobacco smoke (passive or second-hand smoke) can cause lung cancer. Living with a smoker increases a nonsmoker's risk by up to 30%.

Exposure to asbestos – People who are exposed to asbestos are more likely to develop lung cancer or pleural mesothelioma (see previous page). Although the use of asbestos in building materials has been banned across Australia since 2004, there is still asbestos in some older buildings and fences.

Exposure to other elements – People exposed to radioactive gas (radon), such as uranium miners, have an increased risk of lung cancer. Air pollution is another risk factor. Contact with the processing of arsenic, cadmium, steel and nickel, and exposure to diesel in the workplace may also be risk factors.

Family history – You may be at a higher risk if a family member has been diagnosed with lung cancer.

Personal history – Having another lung disease (e.g. lung fibrosis, chronic bronchitis, pulmonary tuberculosis, emphysema) or human immunodeficiency virus (HIV) may increase the risk of lung tumours.

Older age – Lung cancer is most commonly diagnosed in people over the age of 60 years, although it can occur in younger people.

Q: How common is lung cancer?

A: Each year, about 12,200 Australians are diagnosed with lung cancer.⁴ The average age at diagnosis is 72. It is the fifth most common cancer in Australia, accounting for 9% of all cancers diagnosed.⁴ More men than women develop lung cancer.

Q: What are the symptoms?

- A:** The main symptoms of lung cancer are:
- a persistent new cough (lasting more than three weeks) or a change in a cough you've had for a long time
 - breathlessness
 - pain in the chest or shoulder
 - chest infection that lasts more than three weeks or that keeps coming back
 - coughing or spitting up blood.

A person diagnosed with lung cancer may also have symptoms such as fatigue, weight loss, hoarse voice, wheezing, difficulty swallowing, abdominal or joint pain, and enlarged fingertips (finger clubbing).

Having any one of these symptoms does not necessarily mean that you have lung 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 (e.g. x-ray, CT scan) for other conditions.



For an overview of what to expect during all stages of your cancer care, visit cancerpathways.org.au/optimal-care-pathways/lung-cancer. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Q: Which health professionals will I see?

A: Your general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist called a respiratory

Health professionals you may see

GP	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
respiratory (thoracic) physician*	diagnoses diseases of the lungs, including cancer, and recommends initial treatment options
thoracic (chest) surgeon*	diagnoses and performs surgery for cancer and other diseases of the lungs and chest (thorax)
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
radiation therapist	plans and delivers radiation therapy
radiologist*	analyses x-rays and scans; an interventional radiologist may also perform a biopsy under ultrasound or CT, and deliver some treatments
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatments)
cancer care coordinator or lung cancer nurse coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)

physician, who will arrange further tests. If lung cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting.

nurse	administers drugs and provides care, information and support throughout treatment
counsellor, psychologist	help you manage your emotional response to diagnosis and treatment
dietitian	recommends an eating plan to follow while you are in treatment and recovery
speech pathologist	helps with communication and swallowing after treatment
social worker	links you to support services and helps with emotional, practical and financial problems
physiotherapist, occupational therapist	assist with physical and practical issues, including restoring movement and mobility after treatment, and recommending aids and equipment
exercise physiologist	prescribes exercise to help people with medical conditions improve their overall health, fitness, strength and energy levels
palliative care specialist* and nurses	work closely with the GP and cancer team to help control symptoms and maintain your quality of life

** Specialist doctor*



Diagnosis

Your doctors will arrange several tests to make a diagnosis and work out if the cancer has spread beyond the lung. The test results will help them recommend a treatment plan for you.

Initial tests

The first test is usually an x-ray, which is often followed by a CT scan. You may also have a breathing test to check how your lungs are working and blood tests to check your overall health.

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.

CT scan

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

CT scans are usually done at a hospital or radiology clinic. You may be asked to fast (not eat or drink) for several hours before the scan. Before the scan, you will be given an injection of a liquid dye into a vein. This dye is known as contrast, and it makes the pictures clearer. The contrast 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. These sensations should go away quickly, but tell your doctor if you feel unwell.

The CT scanner is a large, doughnut-shaped machine. You will need to lie still on a table while the scanner moves around you. The scan itself is painless and takes only a few minutes, but getting ready for it can take 10–30 minutes.

A low-dose CT scan may be useful for screening healthy people for lung cancer or to follow-up suspicious-looking spots in the lungs. This uses a lower dose of radiation than a regular CT scan and provides a more detailed image than an x-ray. Currently, the Australian Government is looking at how low-dose CT screening could be used in Australia.



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant.

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 then blow out into a machine called a spirometer. You may also have a lung function test before you have surgery (see pages 28–30) or radiation therapy (see pages 31–33).

Blood tests

A sample of your blood will be tested to check the number of red blood cells, white blood cells and platelets (full blood count), and to see how well your kidneys and liver are working.

Tests to confirm diagnosis

If a tumour is suspected after an x-ray or CT scan, you will need further tests to work out if it is lung cancer.

Biopsy

A biopsy is the usual way to confirm a lung cancer diagnosis. A small sample of tissue is taken from the lung, the nearby lymph nodes, or both. The biopsy sample is sent to a laboratory, where a specialist doctor called a pathologist looks at the sample under a microscope. There are various ways to take a biopsy.

CT-guided lung biopsy – You will be given a local anaesthetic. Using a CT scan for guidance, the doctor inserts a needle through the chest wall to remove a small piece of tumour from the outer part of the lungs. You will be monitored for a few hours afterwards, as there is a small risk of damaging the lung. This can be treated if it does occur.

Bronchoscopy – This allows the doctor to look inside the large airways (bronchi) using a bronchoscope, a flexible tube with a light and camera. You will be given either sedation or a light general anaesthetic, then the doctor will pass the bronchoscope into your nose or mouth, down the trachea (windpipe) and into the bronchi. If the tumour is near the bronchi, samples of cells can be collected with a washing or brushing method. During “washing”, fluid is injected into the lung and then removed to be looked at under a microscope. “Brushing” uses a brush-like instrument to remove some cells from the bronchi. If the doctor sees a tumour, they will take a sample.

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

Endobronchial ultrasound (EBUS) – This is a type of bronchoscopy that allows the doctor to see a cancer deeper in the lung. It can also take samples of cells from a tumour or a lymph node in the middle of your chest or next to the airways, or from the outer parts of the lung.

You will have sedation or a general anaesthetic, and the doctor will put a bronchoscope with a small ultrasound probe on the end into your mouth. The ultrasound probe uses soundwaves to create pictures that show the size and position of a tumour. This allows the doctor to measure the tumour and take samples.

After a bronchoscopy, 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 type of biopsy is not used often but may be done if a sample is needed from the lymph nodes found in the area between the lungs (mediastinum). You will have a general anaesthetic, then the surgeon will make a small cut (incision) in the front of your neck and pass a thin tube down the outside of the trachea. You can usually go home on the same day as having a mediastinoscopy, but sometimes you may need to be monitored overnight in hospital.

Thoracoscopy – If other tests are unable to provide a diagnosis, you may have a thoracoscopy. This uses a thoracoscope, a tube with a light and camera, to take a tissue sample from the lungs. It is usually done under general anaesthetic with a type of keyhole surgery called video-assisted thoracoscopic surgery (VATS, see page 29). Sometimes a simpler procedure called a medical thoracoscopy can be done as a day procedure. This is done when you are under sedation.

Biopsy of neck lymph nodes – The doctor may take a sample of cells from the lymph nodes in the neck with a thin needle. This is often done using ultrasound for guidance.

Other samples

In some circumstances, such as if you aren't well enough for a biopsy, mucus or fluid from your lungs may be checked for abnormal cells.

Sputum cytology – This test examines a sample of mucus (sputum) from your lungs to see if there are any cancer cells. Sputum is different from saliva as it contains cells that line the airways. 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. You can keep the sample in your fridge until you take it to your doctor, who will send it to a laboratory to check under a microscope.



A new test known as liquid biopsy involves taking a blood sample and examining it for cancer. Liquid biopsy is still being studied to see how accurate it is, and it is not a routine way to diagnose lung cancer.

Pleural tap – Also known as pleurocentesis or thoracentesis, this procedure drains fluid from around the lungs. It can help to ease breathlessness (see pages 40–41), and the fluid can be tested for cancer cells. It is mostly done with a local anaesthetic, with the doctor using ultrasound to guide the procedure. As with all biopsies, the results need to be interpreted along with the results of physical examination, blood and breathing tests, and imaging tests such as x-ray and CT scan.

Molecular testing

The biopsy sample may be tested for genetic changes or specific proteins in the cancer cells (biomarkers). These tests are known as molecular tests and they help work out which drugs may work best in treating the cancer.

Genetic changes – Genes are found in every cell of the body and are inherited from both parents. If something triggers the genes to change (mutate), cancer may start growing. A mutation that occurs after you are born is not the same thing as genes inherited from your parents. The most common genetic mutations seen in non-small cell lung cancer (NSCLC) are changes in the EGFR (epidermal growth factor receptor), ALK (anaplastic lymphoma kinase) and ROS1 genes. These three mutations can be treated with medicines known as targeted therapy (see pages 36–37). Other mutations linked to NSCLC (such as KRAS) do not yet have a targeted therapy available to treat them.

Proteins – The presence and amount of certain proteins found in the biopsy sample from a NSCLC may suggest the cancer will respond to immunotherapy (see pages 37–38). The most common protein tested for is called PD-L1.

Further tests

If the tests described on pages 14–19 show that you have lung cancer, you will have further tests to see whether the cancer has spread to other parts of your body.

PET-CT scan – This scan combines a PET (positron emission tomography) scan with a CT scan in one machine. It can provide detailed information about the cancer.

A small amount of radioactive glucose solution is injected into a vein, usually in your arm. You will be asked to sit quietly for 30–90 minutes while the glucose solution travels around your body, then you will lie on a table that moves through the scanning machine very slowly. Cancer cells take up more of the glucose solution than normal cells do, so they show up more brightly on the scan.

Sometimes a PET-CT scan is done to work out if a biopsy is needed or to help guide the biopsy procedure.

Other tests – You may also have a CT or MRI (magnetic resonance imaging) scan of the brain. If a PET-CT scan is not available or results are unclear, you may have a CT scan of the abdomen or a bone scan. For more details, talk to your doctor or call Cancer Council 13 11 20.

Staging lung cancer

The tests described above help your specialist work out how far the lung cancer has spread. This is known as staging, and it helps your health care team recommend the best treatment for you.

NSCLC is staged using the TNM system (see the table below). Although the TNM system can be used for SCLC, doctors usually use a two-stage system:

Limited stage – Cancer is only on one side of the chest and in one part of the lung; nearby lymph nodes may also be affected.

Extensive stage – Cancer has spread widely through the lung, to the other lung, to lymph nodes on the other side of the chest or to other areas of the body.

TNM staging system

TNM stands for tumour–nodes–metastasis. Each letter is assigned a number (and sometimes also a letter) to show how advanced the cancer is. This information may be combined to give the lung cancer an overall stage of 1, 2, 3 or 4.

T (tumour)	indicates the size of the tumour and how far the tumour has grown into the lung; ranges from T1a (tumour is 1 cm or less) to T4 (tumour is more than 7 cm, or has grown into nearby structures, or there are two or more separate tumours in the same lobe of a lung)
N (nodes)	shows if the tumour has spread to nearby lymph nodes; ranges from N0 (no spread) to N3 (cancer in lymph nodes on the opposite side of the chest, above the collarbone or at the top of the lung)
M (metastasis)	shows if the tumour has spread to other parts of the body; ranges from M0 (no spread to distant parts of the body) to M1c (cancer has spread and formed more than one tumour in distant parts of the body, e.g. liver, bone)

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 anyone to predict the exact course of the disease. Instead, your doctor can give you an idea about the general outlook for people with the same type and stage of cancer.

To work out your prognosis, your doctor will consider:

- your test results
- the type and stage of lung cancer
- the rate and extent of tumour growth
- how well you and the cancer respond to treatment
- other factors such as your age, fitness and overall health, and whether you're currently a smoker.

Discussing your prognosis and thinking about the future can be challenging and stressful. It is important to know that although the statistics for lung cancer can be frightening, they are an average and may not apply to your situation. Talk to your doctor about how to interpret any statistics that you come across.

As in most types of cancer, the results of lung cancer treatment tend to be better when the cancer is found and treated early. Newer treatments such as targeted therapy and immunotherapy are effective in some people with advanced lung cancer and are bringing hope to those who have lung cancer that has spread. See pages 36–38 for more information about these treatments.



Key points about diagnosing lung cancer

Diagnostic tests

The tests to diagnose lung cancer may include:

- chest x-ray
- CT scan of the chest
- lung function and blood tests
- biopsy – lab tests on a tissue sample removed from your chest by CT-guided lung biopsy, bronchoscopy, endobronchial ultrasound (EBUS), mediastinoscopy or thoracoscopy
- sputum cytology – tests a sample of mucus from the lungs
- pleural tap (pleurocentesis or thoracentesis) – tests a sample of fluid drained from the lungs.

Further tests

Other tests can give more information about the cancer, help work out if it has spread and guide treatment. They may include:

- molecular tests – tests the biopsy sample to identify genes or proteins in the cancer cells
- PET-CT scan
- CT, MRI or bone scans
- tests before surgery or radiation therapy to check how the lungs are working.

Staging and prognosis

The specialist will tell you the stage of the cancer, which describes how much cancer there is and whether it has spread. You may also wish to discuss the prognosis, which is the expected outcome for people with the same type and stage of cancer as you.



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, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see pages 12–13) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes can help or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 59 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist 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 second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* booklet.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

► See our *Understanding Clinical Trials and Research* booklet.



Treatment

Treatment for lung cancer will depend on the type of lung cancer you have, the stage of the cancer, how well you can breathe (your lung function) and your general health. If you are a smoker, your doctor will advise you to stop smoking before you start treatment (see box below).

Understanding the aim of treatment

For early or locally advanced non-small cell lung cancer (stages 1–3 NSCLC) or limited-stage small cell lung cancer (SCLC), treatment may be given with the aim of making all signs and symptoms of the cancer go away. This is called curative treatment.

Because lung cancer causes vague symptoms in the early stages, many people are diagnosed when the cancer is advanced (stage 4 NSCLC or extensive-stage SCLC). This means the cancer has spread outside the lung to other parts of the body. The goal of treatment is to maintain quality of life by controlling the cancer, slowing down its spread and managing any symptoms. This is called palliative treatment.

NSCLC and SCLC are treated in different ways (see page opposite). Treatments to improve breathing are covered in the *Managing symptoms* chapter on pages 40–45.



If you are a current smoker, your health care team will advise you to stop smoking before you start treatment for lung cancer. This is because smoking may make the treatment less effective and side effects worse. To work out a plan for quitting, talk to your doctor or call Quitline on **13 78 48**.

Treatment options by cancer type and stage

Non-small cell lung cancer (NSCLC)

early (stage 1 or 2)	Usually treated with surgery to remove the cancer and nearby lymph nodes. If surgery is not an option or you choose not to have surgery, you may have radiation therapy. Sometimes, chemotherapy may be given after surgery to reduce the risk of the cancer returning.
locally advanced (stage 3)	Can be treated with surgery and chemotherapy or with radiation therapy and chemotherapy. Immunotherapy drugs may also be used. Treatment will depend on where the cancer is in the lung and the number and location of lymph nodes with cancer. In some cases, targeted therapy may be used to slow the spread of the cancer.
advanced (stage 4)	Depending on the symptoms, palliative drug treatment (targeted therapy, immunotherapy or chemotherapy), palliative radiation therapy or both may be used.

Small cell lung cancer (SCLC)

limited stage	Usually treated with chemotherapy and radiation therapy. Surgery is not used.
extensive stage	Mainly treated with palliative chemotherapy, with or without immunotherapy. This depends on the cancer cell type and molecular test results. Palliative radiation therapy may also be given to the primary cancer in the lung and to other parts of the body where the cancer has spread.

Surgery

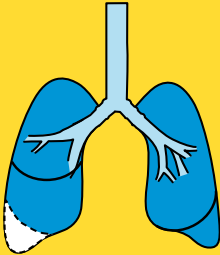
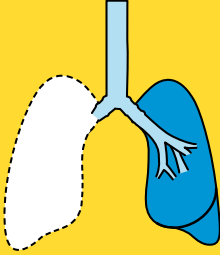
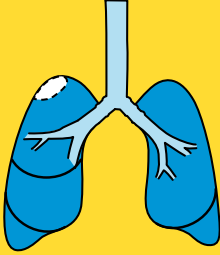
People with early NSCLC (stage 1 or 2) will generally be offered surgery to remove the tumour. How much of the lung is removed depends on several factors:

- the location of the cancer and its size
- your general wellbeing and fitness
- how your lungs are working (lung function).

Because lung cancer causes vague symptoms in the early stages, it is usually diagnosed at a later stage. Surgery is not suitable for most people with late-stage lung cancer. If there is fluid in the lung cavity (called pleural effusion) that keeps coming back, you may have surgery (pleurodesis, see pages 42–43) to control this.

Types of lung surgery

Surgery for lung cancer may remove all or part of a lung.

Lobectomy	Pneumonectomy	Wedge resection
		
One lobe of a lung is removed.	One whole lung is removed.	Only part of a lobe is removed.



Most hospitals in Australia have programs to reduce the stress of surgery and improve your recovery. These are called enhanced recovery after surgery (ERAS) or fast track surgical (FTS) programs. They tell you what to expect each day after surgery.

Removing lymph nodes

During surgery, lymph nodes near the cancer will also be removed to check 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 radiation therapy.

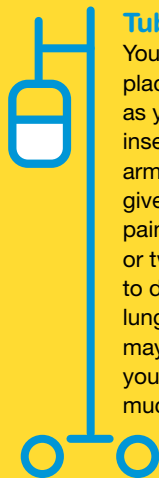
How the surgery is done

There are different ways to perform surgery for lung cancer. Each method has advantages in particular situations – talk to your surgeon about the best approach in your case.

VATS – Lung cancer surgery can often be done using a keyhole approach. This is known as video-assisted thoracoscopic surgery (VATS). In this approach, the surgeon makes a few small cuts (incisions) in the chest wall. A tiny video camera and operating instruments are passed through the cuts, and the surgeon performs the operation from outside the chest. A keyhole approach usually means a shorter hospital stay, faster recovery and fewer side effects.

Thoracotomy – If a long cut is made between the ribs in the side of the chest, the operation is called a thoracotomy. This may also be called open surgery. You will need to stay in hospital for 3–7 days.

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 tubes in your chest to drain fluid and help your lungs expand again. There may be a tube placed into your bladder to check how much urine you pass.



Pain

You may have some pain or discomfort after surgery, but this 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 will improve when tubes are removed from the chest. Pain relief may also help clear phlegm from your chest.

Recovery time

You will probably go home after 3–7 days, but it may take 6–12 weeks to get back to your usual activities. Your treatment team will explain how to manage at home. Walking can improve fitness, clear your lungs and speed up recovery.

Exercises for breathlessness

Gentle exercises as part of a pulmonary rehabilitation program will help improve breathlessness and reduce the risk of developing a chest infection. The hospital physiotherapist will show you how to do these exercises. To continue with a pulmonary rehabilitation program after you leave hospital, talk to your surgeon or visit lungfoundation.com.au.



- › See our *Understanding Surgery* booklet for more information about surgery and recovery.

Radiation therapy

Also known as radiotherapy, radiation therapy is the use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. For lung cancer, the radiation is usually in the form of x-ray beams that come from a machine outside the body. This is called external beam radiation therapy (EBRT). It can be delivered in different ways depending on the type of lung cancer.

Standard EBRT – This is usually given every weekday over several weeks. Treatment aimed at making the signs and symptoms of cancer go away (curative course) may involve 20–33 treatments over 4–6 weeks. Palliative radiation therapy usually involves 1–15 treatments.

Stereotactic body radiation therapy (SBRT) – This is also called stereotactic ablative body radiation (SABR). It is a way of giving a very precise high dose of radiation therapy to small NSCLCs. It is sometimes used instead of surgery. SBRT is often given as 3–4 treatment sessions over a couple of weeks. It is suitable only for tumours that are not close to major airways or major blood vessels.

Radiation therapy may be given on its own, with surgery or with chemotherapy (called chemoradiation). It may be recommended:

- if you are unable or choose not to have surgery
- to treat locally advanced (stage 3) NSCLC or limited-stage SCLC
- after surgery if tests show cancer in the mediastinal lymph nodes, to reduce the risk of the cancer coming back in the mediastinum
- as palliative treatment to improve quality of life by relieving pain or other symptoms (see page 38).

Planning radiation therapy

Before treatment starts, you will have a planning session at the radiation therapy centre to design a treatment plan for you. During this appointment, you will have a CT scan to pinpoint the area to be treated, and marks will be put on your skin so the radiation therapist treats the same area each time.

The radiation oncology team will explain the treatment schedule and discuss possible side effects.

Having radiation therapy

Radiation therapy is delivered using a machine called a linear accelerator. Each treatment day, a radiation therapist will help you to lie on the treatment table and make sure you are in the correct position before leaving the room. Before the radiation therapy is given, you will have an x-ray or CT scan to make sure the correct area is being treated.

When the treatment starts, you will not feel or see anything, but you may hear a buzzing sound from the machine. The treatment itself takes only a few minutes, but a session may last 10–20 minutes because of the time it takes to set up the machine.

Side effects of radiation therapy

The side effects of radiation therapy vary depending on the dose of radiation and the number of treatments. Most are temporary and disappear a few weeks or months after treatment. Radiation therapy itself is painless, but the radiation may affect some tissues of the body and cause some of the side effects discussed opposite.

Discomfort when swallowing and heartburn – These side effects may occur during the treatment period and continue for up to four weeks after treatment ends. Until they improve, you may need to eat soft foods and avoid hot drinks, such as tea and coffee.

Fatigue – Feeling tired is common after radiation therapy. Plan your daily activities so you can rest regularly. You may find physical exercise helps to reduce fatigue (see page 48). It may also help to talk to your family, friends or employer about how they can help you.

Skin changes – The skin on your chest and back may become red or dry, like sunburn. It is important to avoid getting direct sunlight on these areas. Apply a moisturising cream to the skin daily to help look after your skin – talk to your medical team about which products they recommend.

Shortness of breath and cough – Radiation therapy may cause inflammation of the lungs, known as radiation pneumonitis. This may cause shortness of breath, a cough or both. These side effects may happen during treatment, but they are more likely to appear 1–6 months after treatment ends. Radiation pneumonitis is usually temporary and can be treated with steroid (corticosteroid) tablets.

Side effects can change from one treatment session to the next and may build up over time. Tell the radiation oncology team about any side effects you have, as most can be managed.

➤ See our *Understanding Radiation Therapy* booklet and *Fatigue and Cancer* fact sheet, and listen to our “Managing Cancer Fatigue” podcast episode.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells or slow their growth. It can be used at different times:

- before surgery to try to shrink the cancer and make it easier to remove the cancer (neoadjuvant chemotherapy)
- before or in combination with radiation therapy to make radiation therapy more effective (chemoradiation)
- after surgery to reduce the risk of the cancer returning (adjuvant chemotherapy)
- when cancer is advanced – to reduce symptoms and improve quality of life (palliative chemotherapy, see page 38).

Having chemotherapy

Chemotherapy is usually given through a vein (intravenously). Each chemotherapy treatment is followed by a rest period to give your body time to recover. Together, the session and rest period are called a cycle. The number of cycles will depend on the type of lung cancer and side effects you have. You will probably have chemotherapy as an outpatient. Ask your doctor about the treatment plan recommended for you. Some types of chemotherapy come in tablet form and can be taken by mouth (orally). These are sometimes used on an ongoing basis.

Side effects of chemotherapy

Chemotherapy works on cells that are dividing rapidly. Cancer cells divide rapidly, as do some healthy cells such as the cells in your blood, mouth, digestive system and hair follicles. Side effects occur when chemotherapy damages these normal cells. As the body constantly makes new cells, most side effects are temporary. Some side effects are listed on the opposite page.

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

Risk of infections – Chemotherapy drugs can lower the number of white blood cells that fight infections caused by bacteria. If you get an infection caused by a virus, such as a cold, flu or COVID-19, the risk of getting a bacterial infection is increased even more. It is important to have good hand and mouth hygiene, and social distancing and isolation are recommended. If you feel unwell or have a temperature above 38°C, call your doctor immediately or go to the hospital emergency department.

Mouth ulcers – Some chemotherapy drugs cause mouth sores, ulcers and thickened saliva, which make it difficult to swallow. Your treatment team will explain how to take care of your mouth.

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, vomiting or constipation – You will usually be prescribed anti-nausea medicine with your chemotherapy drugs, but some people still feel sick (nauseous) or vomit, or become constipated. Let your treatment team know if you have these side effects, as they may be able to offer another anti-nausea medicine.

› See our *Understanding Chemotherapy* booklet and *Mouth Health and Cancer Treatment* and *Hair Loss* fact sheets, and listen to our “Appetite Loss and Nausea” podcast episode.

Targeted therapy

This is a type of drug treatment that attacks specific features of cancer cells, known as molecular targets, to stop the cancer growing and spreading. The molecular targets are found in or on the surface of cancer cells (for example, they may be genes or proteins). Targeted therapy can often be given by mouth as tablets or capsules. These drugs can be highly effective, but they will only work if the cancer contains the particular gene or protein and, even then, they do not work for everyone. Ask your oncologist about molecular testing (see page 19) and whether targeted therapy is an option for you.

Targeted therapy is currently available for people with NSCLC whose tumours have specific genetic changes (mutations) – see page 19 – when the cancer is advanced or has come back after initial surgery or radiation therapy. 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 oncologist about clinical trials (see page 25).

Cancer cells often become resistant to targeted therapy drugs over time. If the first-line treatment stops working, your oncologist may suggest trying another targeted therapy drug or another systemic treatment. This is known as second-line treatment.

Side effects of targeted therapy

Although targeted therapy may cause less harm to healthy cells, it can still have side effects. These vary depending on the targeted therapy drugs used – common side effects include skin changes such as acne-like rash, tiredness, diarrhoea, nausea or vomiting. It's important to report any new or worsening side effects to your medical team. If left

untreated, some side effects can become serious and may even be life-threatening. For a detailed list of side effects, visit eviq.org.au.

➤ See our *Understanding Targeted Therapy* fact sheet.

Immunotherapy

This is a type of drug treatment that uses the body's own immune system to fight cancer. Immunotherapy drugs known as checkpoint inhibitors block proteins, such as PD-L1, that stop immune cells from recognising and destroying the cancer cells. Once the proteins are blocked, the immune cells can recognise and attack the cancer.

Several checkpoint inhibitors have been approved for most types of advanced NSCLC. One has also been approved for extensive-stage SCLC when it is used together with chemotherapy. Several other checkpoint inhibitors are currently being tested in clinical trials for lung cancer, including using a combination of these drugs.

Checkpoint inhibitors do not work for all lung cancers, but some people have had good results in the short and long term. Your medical oncologist will discuss which treatment approach is best for you.

Side effects of immunotherapy

The side effects of immunotherapy drugs are different to those caused by chemotherapy or targeted therapy. Immunotherapy can cause inflammation of any body organ, which may lead to different side effects depending on which part of the body is inflamed. Common side effects include fatigue, rash, painful joints and diarrhoea. Most people have mild side effects that can be treated easily and usually improve.

Let your medical team know if you have new or worsening symptoms. If left untreated, some side effects can become serious and may even be life-threatening. For a detailed list of side effects, visit eviq.org.au.

➤ See our *Understanding Immunotherapy* fact sheet.

Palliative treatment

If the cancer is advanced when it is first diagnosed or comes back after treatment, your doctor will discuss palliative treatment for any symptoms caused by the cancer. They may refer you to a palliative care specialist. 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 and does not mean giving up hope. Rather, it is about living as fully and comfortably as possible.

Systemic treatment (chemotherapy, immunotherapy and targeted therapy), radiation therapy and surgery may be used palliatively to slow the spread of cancer and control symptoms such as pain or breathlessness. If you are experiencing a build-up of fluid in the lungs, various procedures can drain the fluid and help prevent it building up again. See pages 40–43 in the *Managing symptoms* chapter for more details.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, spiritual and social needs. The team also supports families and carers.

➤ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets, and listen to our advanced cancer podcast.



Key points about treating lung cancer

Choice of treatment

Treatment will depend on the type of lung cancer, its stage, and your general fitness, lung function and suitability for the treatment.

Curative treatment

Treatment aimed at making all signs of the cancer go away. May involve:

- surgery – a whole lung, a lobe or part of a lobe may be removed; not usually used for SCLC
- radiation therapy – uses targeted radiation to damage or kill cancer cells and may be offered on its own or together with surgery or chemotherapy. Side effects may include pain when swallowing, heartburn, fatigue, red or dry skin, shortness of breath or a cough
- chemotherapy – uses drugs to kill cancer cells or slow their growth. Side effects can include anaemia, risk of infections, mouth ulcers, hair loss from head and chest, and nausea, vomiting or constipation
- immunotherapy – uses drugs to help the immune system fight lung cancer. Side effects may include fatigue, rash, painful joints and diarrhoea.

Palliative treatment for advanced lung cancer

The goal of palliative treatment is to slow the spread of cancer and manage symptoms without trying to cure the cancer. Treatment may include:

- chemotherapy and radiation therapy
- targeted therapy – uses drugs that target specific features in cancer cells. Side effects may include acne-like rash, tiredness, diarrhoea, nausea or vomiting
- immunotherapy.



Managing symptoms

For many people, lung cancer is diagnosed at an advanced stage. The main goal of treatment is to manage symptoms and keep them under control for as long as possible. This chapter describes procedures and strategies for managing the most common symptoms of lung cancer. As you may have a number of symptoms, you may be given a combination of treatments. Keep in mind that you won't necessarily experience every symptom listed here.

Breathlessness

Many people with lung cancer have difficulty breathing and shortness of breath (dyspnoea) before or after diagnosis. These can occur for several reasons, such as the cancer itself and a reduction in lung function, a decrease in fitness level due to reduced physical activity or a build-up of fluid between the linings of the lung (pleural effusion).

If breathlessness is caused by fluid build-up in the pleural cavity (the space between the linings of the lung), you may need to have surgery:

- pleural tap to drain the fluid (see opposite)
- pleurodesis to stop fluid building up again (see page 42)
- an indwelling pleural catheter (see page 43).

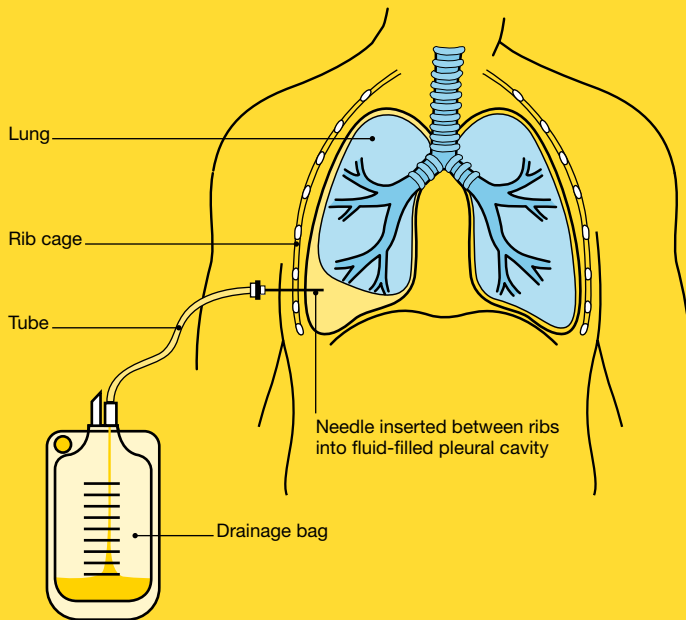
If the cancer is blocking one of the main airways, a doctor may be able to use a laser to open up the airway and improve breathing. You may also be referred to a pulmonary rehabilitation course to learn how to manage breathlessness. This will include exercise training, breathing techniques, ways to clear the airways, and tips for pacing yourself. For some ideas about how to manage breathlessness at home, see the suggestions on pages 44–45.

Having a pleural tap

For some people, fluid may build up in the space between the two layers of thin tissue covering the lung. This is called pleural effusion and it can put pressure on the lung, making it hard to breathe.

Having a pleural tap can relieve this symptom. The procedure is also known as pleurocentesis or thoracentesis. 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. The fluid can then be drained, which will take about 30–60 minutes. You usually don't have to stay overnight in hospital after a pleural tap. A sample of the fluid is sent to a laboratory for testing.





Lung Foundation Australia can provide more information about living with lung cancer. Visit lungfoundation.com.au/patients-carers/conditions/lung-cancer/resources to find written information and videos. You can also contact their Lung Cancer Support Nurse by calling **1800 654 301**.

Pleurodesis

Pleurodesis means closing the pleural cavity. Your doctors might recommend this procedure if the fluid builds up again after you have had a pleural tap. It may be done by a thoracic surgeon or respiratory physician in one of two ways, depending on how well you are and what you would prefer:

VATS pleurodesis – This method uses a type of keyhole surgery called video-assisted thoracoscopic surgery (VATS). You will be given a general anaesthetic, then a tiny video camera and operating instruments will be inserted through one or more small cuts in the chest. After all fluid has been drained, the surgeon then puffs some sterile talcum powder into the pleural cavity. This causes inflammation that helps fuse the two layers of the pleura together and prevents fluid from building up again. You will stay in hospital for a few days.

Bedside talc slurry pleurodesis – If you are unable to have a general anaesthetic, a pleurodesis can be done under local anaesthetic while you're in bed. A small cut is made in the chest, then a tube is inserted into the pleural cavity. Fluid can be drained through the tube into a bottle. Next, sterile talcum powder mixed with salt water (a “slurry”) is injected through the tube into the pleural cavity. To help move the talc

slurry throughout the pleural cavity, nurses will help you move into various positions for about 10 minutes at a time. The entire process takes about an hour.

A slurry pleurodesis usually requires a hospital stay of two or three days. After the procedure, some people experience a burning pain in the chest for 24–48 hours, but this can be eased with medicines.

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 and who are unable to or prefer not to have pleurodesis.

You will be given a local anaesthetic, then the doctor inserts the catheter through the chest wall into the pleural cavity. One end of the tube is inside the chest, and the other stays outside the body for drainage. This end is coiled and tucked under a small dressing.

When fluid builds up and needs to be drained (usually once or twice a week), the end of the catheter is connected to a small bottle. You can manage the catheter at home with the help of a community nurse. A family or friend can also be taught how to clear the drain.

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

Improving breathlessness at home

It can be distressing to feel short of breath, but a range of simple strategies can provide some relief at home.

Treat other conditions

Let your doctor know if you feel breathless. Other conditions, such as anaemia or a lung infection, may also make you feel short of breath, and these can often be treated.



Sleep more upright

Use a recliner chair or prop yourself up in bed to help you sleep in a more upright position.

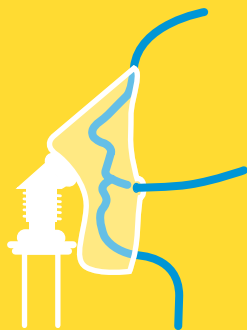


Ask about medicines

Talk to your doctor about medicines, such as a low dose of morphine, to ease breathlessness. Make sure your chest pain is well controlled, as pain may stop you breathing deeply.

Check if equipment could help

Ask your health care team about equipment to manage breathlessness. To improve the capacity of your lungs, you can blow into a device called an incentive spirometer. You may be able to use an oxygen concentrator at home to deliver oxygen to your lungs, or a portable oxygen cylinder for outings. If you have a cough or wheeze, you may benefit from a nebuliser, a device that delivers medicine into your lungs.





Modify your movement

Some types of gentle exercise can help but check with your doctor first. A physiotherapist, exercise physiologist or occupational therapist from your treatment centre can explain how to modify your activities to improve breathlessness.



Create a breeze

Use a handheld fan to direct a cool stream of air across your face if you feel short of breath when not exerting yourself. Sitting by an open window may also help.

Relax on a pillow

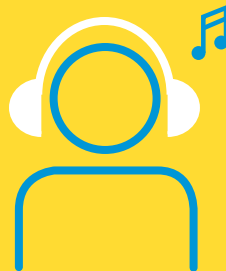
Lean forward on a table with an arm crossed over a pillow to allow your breathing muscles to relax.



Find ways to relax

Listen to a relaxation recording or learn other ways to relax. This can allow you to control anxiety and breathe more easily. Cancer Council has free relaxation and meditation recordings available as CDs and online. Some people find breathing exercises, acupuncture and meditation helpful.

► See our *Understanding Complementary Therapies* booklet.



Pain

Pain can be a symptom of lung cancer and a side effect of treatment. Tell your treatment team if you are in pain. If pain is not controlled, it can affect your wellbeing and how you cope with treatments.

There are different ways to control pain. Aside from medicines, various procedures can manage fluid build-up that is causing pain (see pages 40–43). Radiation therapy and chemotherapy can reduce pain by shrinking a lung tumour. Surgery may help treat pain from bones: for example, if the cancer has spread to the spine and is pressing on nerves (nerve compression). If pain is hard to manage, a palliative care or pain specialist can help find the right pain control for you.



Coping with pain

- Keep track of your pain in a symptom diary – note what the pain feels like, how intense it is, where it comes from and travels to, how long it lasts and if it goes away with a specific medicine or another therapy such as a heat pack.
- Allow a few days for your body to adjust to the dose of pain medicine and for drowsiness to improve.
- Take pain medicine regularly as prescribed, even when you are not in pain. It's better to stay on top of the pain.
- Use a laxative regularly to prevent or relieve constipation from pain medicines.
- Try learning relaxation or meditation techniques to help you cope with pain. Cancer Council has recordings available as CDs and online.
- ▶ See our *Overcoming Cancer Pain* booklet and listen to our podcast episodes on pain.

Poor appetite and weight loss

Some people stop feeling interested in eating and lose weight before lung cancer is diagnosed. These symptoms may be caused by the disease itself, or by feeling sick, having difficulty swallowing, being breathless, or feeling down (see page 53).

Eating well will help you cope better with day-to-day living, treatment and side effects, and improve your quality of life. Consider talking to a dietitian who is experienced in treating people with cancer. A dietitian can help you make small dietary changes to keep you well nourished and recommend protein drinks and other nutritional supplements if needed. You can ask your treatment team to refer you to a dietitian.



Eating when you have little appetite

- Choose high-kilojoule and high-protein foods (e.g. add cheese or cream to meals).
- Eat smaller portions more often (5–6 meals per day), instead of three larger meals.
- Avoid drinking fluids at mealtimes, which can fill you up too quickly.
- Eat moist food such as scrambled eggs. Moist food tends to be easier to eat and will cause less irritation if you have a sore mouth.
- Try eating fresh salads or cold foods if hot food smells make you feel sick. Avoid fatty or sugary foods if these make you feel sick.
- Add ice-cream or fruit to a drink to increase kilojoules.
- Eat more of your favourite foods – follow your cravings.
- See our *Nutrition and Cancer* booklet and listen to our “Appetite Loss and Nausea” podcast episode.

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 may not go away with rest or sleep. 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 be a side effect of drugs or a sign of depression, which can all be treated. There are also many hospital and other programs available to help you manage fatigue.



Managing fatigue

- Set small, manageable goals for the day, and rest before you get too tired.
- Plan breaks throughout the day when you are completely still for a while. An eye pillow can help at these times.
- Say no to things you really don't feel like doing.
- Leave plenty of time to get to appointments.
- Ask your doctor about what sort of exercise would be suitable. A physiotherapist or exercise physiologist can help with safe and appropriate exercise plans.
- An occupational therapist can show you relaxation techniques, breathing exercises and ways to conserve your energy.
- Consider acupuncture – some people find it helps with fatigue.
- ▶ See our *Fatigue and Cancer* fact sheet and listen to our “Managing Cancer Fatigue” podcast episode.

Difficulty sleeping

Getting a good night's sleep is important for maintaining your energy levels, reducing fatigue and improving mood. Pain, breathlessness, anxiety or depression can make it hard to sleep. Some medicines can also disrupt sleep. If you already had sleep problems before the lung cancer diagnosis, these could become worse.

Talk to your doctor about what might help improve your ability to sleep. Your medicines may need adjusting or sleep medicines may be an option. Seeing a counsellor may help if you feel anxious or depressed. The box below gives some strategies that people with cancer have found helpful.



Getting a better night's sleep

- Try to do some gentle physical activity every day. This will help you sleep better. A physiotherapist or exercise physiologist can tailor an exercise program for you. See our *Exercise for People Living with Cancer* booklet.
- Limit or cut out alcohol, caffeinated drinks, nicotine and spicy food.
- Avoid watching television or using a computer, smartphone or tablet, before bed, as their light tells your body it's time to wake up.
- Follow a regular routine before bed and set up a calm sleeping environment. Ensure the room is dark, quiet and a comfortable temperature.
- Practise mindfulness, such as listening to a meditation recording. Or listen to gentle relaxation music.
- ▶ Listen to our "Sleep and Cancer" podcast episode.



Key points about managing symptoms

Shortness of breath

Breathlessness can be managed with:

- surgical procedures – including pleural tap to drain fluid, pleurodesis to stop fluid building up, and an indwelling pleural catheter to drain fluid
- pulmonary rehabilitation – including exercise training and breathing techniques
- medicines – such as low doses of morphine
- self-management – such as sleeping upright, gentle exercise, using a fan, positioning pillows and relaxation techniques.

Pain

Pain can be managed with:

- pain medicines
- other medicines for nerve pain
- surgical procedures that drain fluid or reduce the size of the cancer
- radiation therapy or chemotherapy
- self-management – such as keeping a symptom diary, relaxation and meditation.

Other symptoms

Many people with lung cancer also experience:

- poor appetite and weight loss – see a dietitian for ways to make food nutritious and appealing
- fatigue – pace yourself, accept help and find ways to exercise; an occupational therapist can help you learn ways to manage fatigue and conserve energy, and a physiotherapist or exercise physiologist can prepare a suitable exercise plan for you
- difficulty sleeping – try to do some gentle physical activity every day, have a set bedtime routine and avoid watching television or using a computer, smartphone or tablet before bed.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

› See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can maintain and improve lung function. It can also reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel and your doctor's advice.

› See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

› See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

Sexuality – 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.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See our *Fertility and Cancer* booklet.



Living with lung cancer

Life with a lung cancer diagnosis can present many challenges. Take some time to adjust to the physical and emotional changes, and establish a daily routine that suits you and the symptoms you're coping with. Your family and friends may also need time to adjust.

Because lung cancer is often diagnosed at an advanced stage, treatment may be ongoing and it may be hard to accept that life won't return to normal. If the cancer was diagnosed at an early stage, you may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back.

Cancer Council 13 11 20 can provide you with information and help you connect with other people with a similar diagnosis (see page 56).

- See our *Living with Advanced Cancer* or *Living Well After Cancer* booklet.

Dealing with feelings of sadness

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

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline **13 11 14** or visit lifeline.org.au.

Follow-up appointments

Whether treatment ends or is ongoing, you will have regular appointments to manage any long-term side effects and check that the cancer hasn't come back or spread. During these check-ups, you will usually have a physical examination and you may have chest x-rays, CT scans and blood tests. You will also be able to discuss how you're feeling and mention any concerns you may have.

Check-ups after treatment are likely to happen every 3–6 months for the first couple of years and 6–12 months for the following three years. When a follow-up appointment or test is approaching, many people feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Between appointments, let your doctor know immediately of any new health problems or change in symptoms.

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 after diagnosis. If the cancer returns, your doctor will discuss treatment options with you. These will depend on the type of lung cancer, where the cancer has recurred, and the stage and grade.

Whichever treatment you are given or choose to have, support from palliative care specialists and nurses can help you live with fewer symptoms. Talk to your doctor about how to get this support.

➤ See our *Understanding Palliative Care* booklet.



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ 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*

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit cancercouncil.com.au/OC.



Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian	
Cancer Council Australia	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Australasian Lung Cancer Trials Groups	altg.com.au
Australian Clinical Trials	australianclinicaltrials.gov.au
Cancer Australia	canceraustralia.gov.au
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
eviQ Cancer Treatments Online	eviq.org.au
Department of Health	health.gov.au
Healthdirect Australia	healthdirect.gov.au
Lung Foundation Australia	lungfoundation.com.au
Optimal Care Pathways	cancerpathways.org.au
Palliative Care Australia	palliativecare.org.au
Radiation Oncology: Targeting Cancer	targetingcancer.com.au
Services Australia (includes Medicare and Centrelink)	servicesaustralia.gov.au
International	
American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk



Caring for someone with cancer

You may be reading this booklet because you are caring for someone who has been diagnosed with lung cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

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

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Associations – Carers Australia provides information and advocacy for carers, and is the national peak body representing them to the Australian Government. Visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of lung cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

After treatment

- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?



Glossary

adenocarcinoma

Cancer that starts in the mucus-producing (glandular) cells that form part of the lining of the lungs and other internal organs.

advanced cancer

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body. Treatment can often still control the cancer and manage symptoms.

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. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

asbestos

A naturally occurring silicate mineral that forms long crystallised fibres.

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.

breathlessness

The sensation of shortness of breath or difficulty breathing. Also called dyspnoea.

bronchioles

The smallest airways (tubes) that carry air into the outer part of a lung.

bronchoscopy

A test that uses a flexible tube with a light and camera to examine the airways and lungs and take tissue samples.

bronchus (plural: bronchi)

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

cells

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

chemoradiation

Treatment that combines chemotherapy with radiation therapy. Also called chemoradiotherapy.

chemotherapy

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

CT scan

Computerised tomography scan. This scan uses x-rays to create detailed cross-sectional pictures 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 reduces the lung surface, causing breathing difficulties.

endobronchial ultrasound (EBUS)

A type of bronchoscopy that uses a

flexible tube with a small ultrasound probe to examine the airways and lungs and take tissue samples.

external beam radiation therapy (EBRT)

Radiation therapy delivered to the cancer from outside the body.

genes

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

genetic markers

A gene or DNA sequence associated with a particular characteristic.

immune system

A network of cells and organs that defends the body against attacks by foreign invaders, such as bacteria and viruses. Includes the lymphatic system.

immunotherapy

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

intravenous (IV)

Injected into a vein.

large cell undifferentiated carcinoma

Cancer in which the 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.

locally advanced cancer

Cancer that has spread to nearby organs or blood vessels.

lungs

The two spongy organs in the chest. The lungs are made up of many tiny air sacs and are used for breathing. They are part of the respiratory system.

lymph nodes

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

malignant

Cancerous. Malignant cells can spread (metastasise) 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.

metastasis (plural: metastases)

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

molecular testing

Looks for genetic changes or specific proteins in the cancer cells (biomarkers).

MRI scan

Magnetic resonance imaging scan. A scan that uses magnetic fields 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 the gene.

non-small cell lung cancer (NSCLC)

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

palliative treatment

Medical treatment to help manage pain and other symptoms of advanced cancer.

parietal pleura

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

PET-CT scan

Positron emission tomography scan combined with a CT scan.

pleura

The mesothelium (thin sheet of tissue) that lines the chest wall and covers the lungs.

It has two layers: parietal and visceral.

pleural cavity (pleural space)

The space between the layers of the pleura; normally contains a thin film of fluid.

pleural effusion

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

pleural mesothelioma

Cancer that affects the layers of tissue that cover the lungs (the pleura).

pleural tap

A procedure in which a hollow needle is inserted between the ribs to drain excess fluid. Also called pleurocentesis or thoracentesis.

pleurodesis

An injection of sterile talcum powder into the pleural cavity. This causes inflammation that closes the space and prevents fluid building up again.

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.

pulmonary

Relating to the lungs.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

sedation

A drug that causes a state of calm.

small cell lung cancer (SCLC)

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

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)

Cancer that starts in the squamous cells, which are flat cells found on the skin's surface or in the lining of the lungs or other organs.

staging

Performing tests to work out how far a cancer has spread.

stereotactic body radiation therapy (SBRT)

A type of radiation therapy that delivers

high doses of radiation very precisely. Also called stereotactic ablative body radiation therapy.

systemic treatment

Cancer drugs that spread throughout the whole body. Includes chemotherapy, targeted therapy and immunotherapy.

targeted therapy

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread.

thoracentesis

See pleural tap.

thoracoscopy

A procedure for looking at the lungs with a thoracoscope, a thin tube with a tiny video camera. See also VATS.

thoracotomy

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

trachea (windpipe)

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)

Keyhole surgery performed through small cuts in the chest using a thoracoscope for guidance. See also thoracoscopy.

visceral pleura

The inner layer of the pleura that lines the lung surface.

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:

- cancerCouncil.com.au/words
- cancervic.org.au/glossary

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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 other Pink events, or hold your own fundraiser or become a volunteer.

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

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

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

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

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



Cancer Council

13 11 20

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

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

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

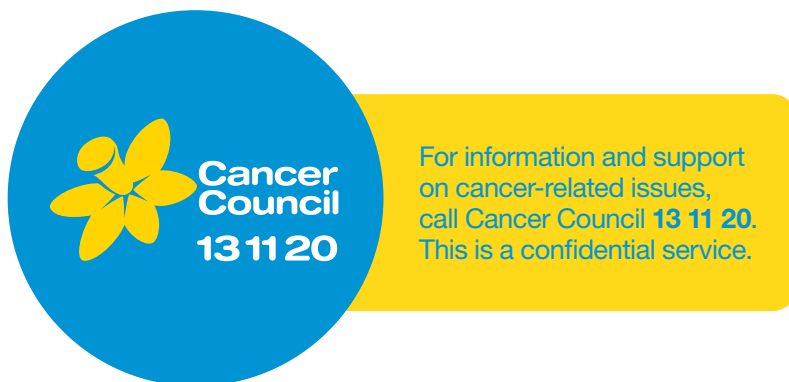
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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



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

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



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*