



Understanding Lung Cancer

A guide for people with cancer,
their families and friends

Cancer
information

For information & support, call

13 11 20



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Note to reader

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

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

Cancer Council

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



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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 also 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 clinical practice guidelines for lung cancer.¹

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

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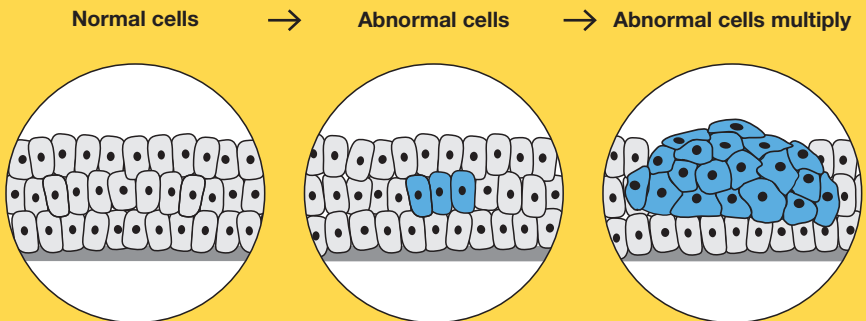
What is cancer?

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 or breast 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

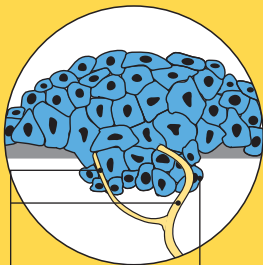


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

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 there may be symptoms coming from the bones.

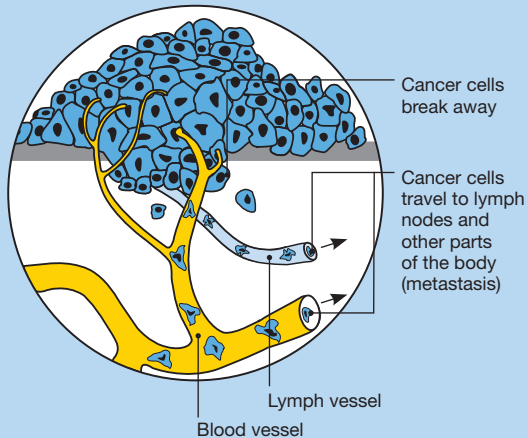
How cancer spreads

→ Malignant cancer



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue





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 look like two large, spongy cones. Each lung is made up of sections called lobes – the left lung has two lobes and the right lung has three.

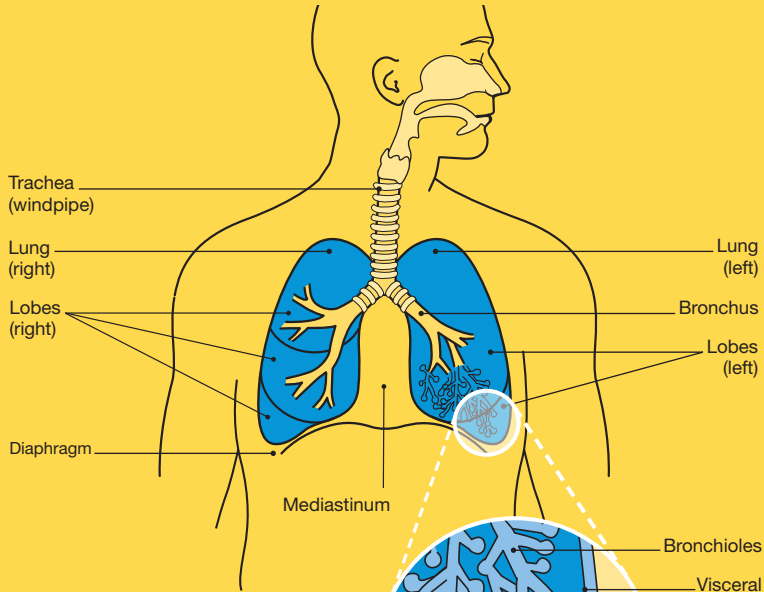
Diaphragm – The lungs rest on the diaphragm, which is a wide, thin muscle that helps with breathing.

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 structures that collect and destroy bacteria and viruses.

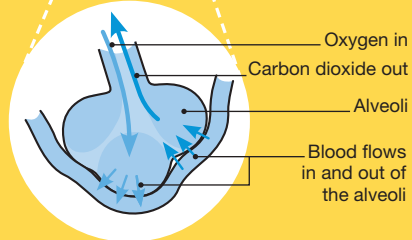
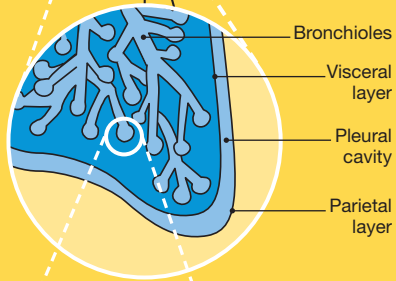
Pleura – The lungs are covered by two layers of a thin sheet of tissue called the pleura, which is about as thick as plastic cling wrap. The inner layer (the visceral layer) lines the lung surface, and the outer layer (the parietal layer) lines the chest wall and diaphragm. The layers are separated by a film of fluid that lets them slide over each other. This 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 pass oxygen into the blood and collect the waste gas (carbon dioxide). When you breathe out (exhale), carbon dioxide is removed from the body and released back into the atmosphere.





Key questions

Q: What is lung cancer?

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

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: <ul style="list-style-type: none">• 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 to 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 and on the next page 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 males and 65% in females are estimated to be a result of tobacco smoking. 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 one-fifth (21%) of people who are diagnosed with lung cancer have never been smokers.²

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 20–30%.³

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) in the workplace, such as uranium miners, have an increased risk of lung cancer. Contact with the processing of arsenic, cadmium, steel and nickel may also be a risk factor.

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 HIV infection may increase the risk of lung tumours.

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

Q: How common is lung cancer?

A: Each year, about 11,500 Australians are diagnosed with lung cancer.⁴ The average age at diagnosis is 71. It is the fifth most common cancer in Australia and accounts for 9% of all cancers diagnosed.⁵ More men than women develop lung cancer. The risk of being diagnosed before the age of 85 is 1 in 13 for men and 1 in 21 for women.⁴

Q: What are the symptoms?

A: The main symptoms of lung cancer are:

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

A person diagnosed with lung cancer may also have experienced 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.

Lung cancer symptoms can be vague and the disease is often discovered when it has spread to other parts of the body. Sometimes, there are no symptoms and the cancer is found during routine tests (often an x-ray or 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 organise the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a respiratory 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

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
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
cancer care coordinator or lung cancer nurse coordinator	coordinates care, liaises with 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)

professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care. The health professionals you see will depend on whether the lung cancer has spread.

nurse	administers chemotherapy and other drugs and provides care, information and support throughout 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 or financial problems
physiotherapist, occupational therapist	assist with physical and practical issues, including restoring movement and mobility after treatment and recommending aids and equipment
counsellor, psychologist	help you manage your emotional response to diagnosis and treatment
palliative care specialist* and nurses	work closely with the GP and cancer specialists to help control symptoms and maintain your quality of life

** Specialist doctor*



Diagnosis

Your doctors will perform a number of tests to make a diagnosis, and work out whether the cancer has spread beyond the lung. The test results will help them recommend a treatment plan for you.

Initial tests

To investigate abnormal symptoms, the first test is usually an x-ray, often followed by a CT scan. You may also have a 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. After a chest x-ray, you may need more detailed tests.

CT scan

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

“ 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

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 to make the pictures clearer and easier to read. Before the scan, you will be given an injection of dye into a vein in your arm. This dye is known as the contrast and it makes the pictures clearer. The 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, but these sensations won't last long.

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



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 are diabetic, have 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 blow out into a machine called a spirometer.

Blood tests

A sample of your blood will be tested to check the number of cells (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 whether 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 and/or nearby lymph nodes, then a specialist doctor called a pathologist examines the sample under a microscope. There are various ways to take a biopsy.

CT-guided lung biopsy – 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 observed for a few hours afterwards, as there is a small risk of damaging the lung.

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 have sedation or a 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 technique. During “washing”, fluid is injected into the lung and removed for examination. “Brushing” uses a brush-like instrument to remove some cells from the bronchi.

Endobronchial ultrasound (EBUS) – This is a bronchoscopy that allows the doctor to see cancers 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 use a bronchoscope with a small ultrasound probe on the end. The ultrasound probe uses soundwaves to create pictures that show the size and position of the tumour and allow the doctor to measure it.

After an EBUS, you may have a sore throat or cough up a small amount of blood. These side effects usually pass quickly, but tell your medical team how you are feeling so they can monitor you.

Mediastinoscopy – This is not used as often as other biopsy methods, but is sometimes used if a sample is needed from the lymph nodes found between the lungs (mediastinum). You will have a general anaesthetic, then a small cut (incision) will be made in the front of your neck and a thin tube passed down the outside of the trachea. A mediastinoscopy is usually a day procedure, but you may need to stay overnight in hospital for observation.

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). After VATS, you will have a drain coming from your side and stay in hospital for a few days. Sometimes a simpler procedure called a medical thoracoscopy can be done as a day procedure under sedation.

Biopsy of neck lymph nodes – A sample of cells may be taken from the lymph nodes in the neck with a thin needle. This is done using ultrasound for guidance.



A new technique known as liquid biopsy involves taking a blood sample and examining it for signs of disease. At this stage, however, liquid biopsy is not a routine way to diagnose lung cancer.

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. Sputum is different to 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. The sample can be refrigerated until you take it to your doctor, who will send it to a laboratory to check under a microscope.

Pleural tap – Also known as pleurocentesis or thoracentesis, a pleural tap is a procedure to drain fluid from around the lungs. While it is often done to ease breathlessness (see page 41), the fluid can be tested for cancer cells. It is mostly performed under local anaesthetic using ultrasound for guidance. 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). The tests are known as molecular tests and help work out which drugs may be most effective 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 are changes in the EGFR (epidermal growth factor receptor), ALK (anaplastic lymphoma kinase) and ROS1 genes. Some mutations can be treated with medicines known as targeted therapy (see pages 36–37), but others do not yet have a targeted therapy available.

Proteins – Certain proteins found in some types of non-small cell lung cancer suggest that the cancer may respond to immunotherapy (see pages 37–38). These include proteins known as PD-1 and PD-L1.

Quitting smoking

Many people diagnosed with lung cancer have already stopped smoking, often years before, and some have never smoked at all. If you are a smoker, your doctors 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.

Quitting can be hard, especially if you're already feeling anxious about the cancer diagnosis, so it

is important to seek support. This may include a combination of:

- counselling, either over the phone, online or face-to-face
- nicotine replacement therapy (patches, lozenges, gum, sprays or inhalers)
- medicines that reduce nicotine craving and withdrawal symptoms.

To work out a plan for quitting, talk to your doctor, call Quitline **13 7848** or visit **quitnow.gov.au**.

Further tests

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

PET scan – A PET (positron emission tomography) scan is a specialised imaging test available at most major hospitals. You will be asked to fast (not eat or drink) for a number of hours before the scan. A small amount of radioactive glucose solution will be injected into a vein, usually in your arm. You will need 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 brighter on the scan.

Other tests – You may also have a CT scan of the abdomen to check the liver; a bone scan; and a CT or MRI scan of the brain. For more information about these tests, 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 cancer has spread. This is known as staging, and it helps your health care team recommend the best treatment for you.

Non-small cell lung cancer and small cell lung cancer can both be staged using the TNM system. See the table opposite for more information about this staging system.

TNM 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 I, II, III or IV. The staging system for lung cancer is complex and often changes, so ask your doctor to explain how it applies to you.

T (tumour)	Indicates the size of the tumour and the depth of any tumour invasion into the lung. Ranges from T1a (tumour is less than 1 cm) 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).

Lung cancer by stage

stages I and II	early lung cancer
stage III	locally advanced lung cancer
stage IV	advanced or metastatic lung cancer



Lillian's story

Two days after my 34th birthday, I woke up with a sore shoulder and arm. I didn't think too much of it because the pain went away quickly.

After I felt a lump on my left collarbone, I mentioned it to my dad and brother because they're doctors. They said it was probably because I'd had a cough in the past few weeks but to get an ultrasound.

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

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

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

A lot of the people I've met with lung cancer say they're guarded about their diagnosis. One carer said she didn't tell anyone for three years that her spouse had lung cancer for fear of being stigmatised.

There needs to be a lot more compassion. I think that taking away the stigma will lead to greater funding for research. I am feeling hopeful about my future. It's important to me to stay in the moment and appreciate what I have.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for 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 of lung cancer
- the rate and extent of tumour growth
- how well you respond to treatment
- other factors such as your age, fitness and overall health, and whether you're currently a smoker.

As in most types of cancer, the results of lung cancer treatment tend to be better when the cancer is found and treated early. However, new treatments such as targeted therapy and immunotherapy have been effective in some people with advanced lung cancer. 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
- 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 – lab tests on a sample of mucus from the lungs
- pleural tap – lab tests on a sample of fluid drained from the lungs.

Further tests

Other tests can give more information about the cancer and help doctors work out whether it has spread. These tests can guide treatment and may include:

- molecular tests – lab tests on the biopsy sample to identify particular genetic mutations in the cancer
- PET scan to check for cancer in other parts of the body
- CT scan of the abdomen or brain
- bone scan
- MRI scan of the brain.

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 – in some cases, 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 or recording the discussion can help. 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. NSCLC and SCLC are treated in different ways, as shown in the table below.

Treatment options by type and stage

Non-small cell lung cancer (NSCLC)

early (stage I or II)

Usually treated with surgery to remove the cancer and nearby lymph nodes. If surgery is not an option, radiation therapy is offered. Sometimes, chemotherapy may be given after surgery or with radiation therapy.

locally advanced (stage III)

Can be treated with surgery and chemotherapy or with radiation therapy and chemotherapy. Treatment will depend on the number and location of lymph nodes with cancer.

advanced (stage IV)

Depending on the symptoms, palliative chemotherapy and/or palliative radiation therapy may be offered. New targeted therapy and immunotherapy drugs may also be an option.

Small cell lung cancer (SCLC)

early or locally advanced (stages I–III)

Usually treated with chemotherapy and radiation therapy. Surgery is not used.

advanced (stage IV)

Mainly treated with palliative chemotherapy. Palliative radiation therapy may also be given to the brain, spine, bone or other parts of the body where the cancer has spread.

Understanding the aim of treatment

For early or locally advanced lung cancer (stages I–III), treatment may be given with the aim of making all signs and symptoms of the cancer go away (curative treatment).

Because lung cancer rarely causes obvious symptoms in the early stages, many people are diagnosed when the cancer is advanced (stage IV). This means the cancer has spread outside the lung to other parts of the body. The goal of treatment will be to maintain quality of life by controlling the cancer, slowing down its spread and managing any symptoms (palliative treatment). Specific treatments to improve breathing are covered in the *Managing symptoms* chapter on pages 40–43.

Surgery

People with early non-small cell lung cancer (stage I or II) will generally be offered surgery to remove the tumour. How much of the lung is removed depends on the location of the cancer, its size, your general wellbeing and fitness, as well as your lung function.

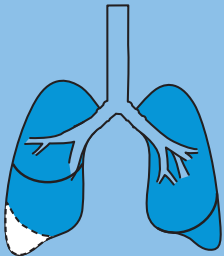
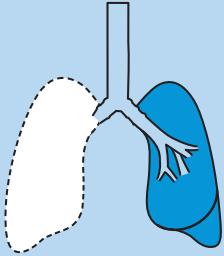
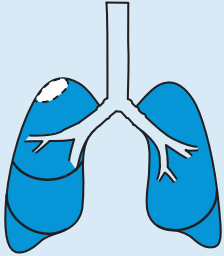
Lung cancer is usually diagnosed at a later stage once it has caused symptoms, so most people with lung cancer will not have surgery.

Removing lymph nodes

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

Types of lung surgery

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

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

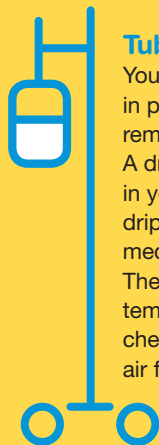
How the surgery is done

The surgery can be done in different ways. Talk to your surgeon about the best approach in your case.

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

VATS – It's becoming more common for lung surgery to be done with a keyhole approach. This is known as video-assisted thoracoscopic surgery (VATS). The surgeon makes a few small cuts in the chest wall, inserts a tiny video camera and operating instruments, and performs the operation from outside the chest. A keyhole approach usually means a shorter hospital stay, faster recovery and fewer side effects.

What to expect after surgery



Tubes and drips

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



Pain

Some degree of pain or discomfort is common 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 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 resume your usual routine and activities. Your treatment team will explain how to manage at home. Walking can improve fitness, clear your lungs and speed up recovery.

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.

Thermal ablation

Some people with very early lung cancer may be offered thermal ablation as an alternative to surgery. Thermal ablation involves inserting needles or probes into the cancer to destroy the cancer cells with heat. Only one treatment is needed. A CT scan is used to guide the needles into the right position. Thermal ablation is not painful, but you may have a general anaesthetic to make you more comfortable during the procedure.

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) and it can be delivered in different ways (see table, next page).

Radiation therapy may be offered on its own or in combination with surgery or chemotherapy, and may be recommended:

- to treat an early lung cancer if you are unable to have surgery
- to treat locally advanced (stage III) NSCLC or stages I–III 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).

The radiation oncology team will plan your treatment, explain the treatment schedule and discuss possible side effects (see pages 33–34).

Types of external beam radiation therapy

Radiation therapy can be used for all types of lung cancer, but may be delivered in different ways depending on the type of lung cancer.

standard external beam radiation therapy (EBRT)	<ul style="list-style-type: none">• This is usually given every weekday over several weeks.• A curative course may involve a series of 20–33 treatments over 4–5 weeks.• Palliative radiation therapy usually involves 1–10 treatments.
stereotactic body radiation therapy (SBRT)	<ul style="list-style-type: none">• This is a way of giving highly focused radiation therapy to small NSCLC tumours, while the surrounding tissue receives a low dose. It is delivered from multiple beams that meet at the tumour.• SBRT often involves four treatment sessions over a couple of weeks.• This type of radiation therapy is only suitable for tumours that are not close to major airways, blood vessels or the spinal cord.
hyperfractionated radiation therapy	<ul style="list-style-type: none">• This means having a slightly higher dose of radiation therapy each day so that the entire course is delivered over a shorter period of time.• The total dose of radiation is roughly the same as the total dose you would have for standard radiation therapy.• Hyperfractionated radiation therapy is mostly used for SCLC.
concurrent chemoradiation	<ul style="list-style-type: none">• This means having chemotherapy and radiation therapy at the same time.

Having radiation therapy

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

Side effects of radiation therapy

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

Difficulty 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 change to a soft food diet and avoid hot drinks, such as tea and coffee.

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

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

Shortness of breath and cough – Radiation therapy may cause inflammation of the lungs, known as radiation pneumonitis. This may cause shortness of breath and/or a cough, sometimes during

treatment but more likely one to six months after treatment ends. Radiation pneumonitis is usually temporary and can be treated with steroid (cortisone) tablets.

Side effects can change from one period of radiation therapy 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 listen to our “Managing Cancer Fatigue” podcast episode.

Chemotherapy

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

- before surgery to try to shrink the cancer and make the operation easier (neoadjuvant chemotherapy)
- before or during 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 delivered into a vein (intravenously). Each chemotherapy treatment is called a cycle and is followed by a rest period to give your body time to recover. The number of cycles will depend on the type of lung cancer you have and the side effects you experience. You will probably have chemotherapy as an

outpatient, which means you won't have to stay overnight. 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. Unlike cancer cells, normal cells can recover, so most side effects are temporary. Side effects vary depending on the drugs used and from person to person.

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

Risk of infections – Chemotherapy drugs lower the number of white blood cells that fight infections, so you will be more likely to develop colds or flu. 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 or vomiting – You will usually be prescribed anti-nausea medicine with your chemotherapy drugs, but some people still feel sick (nauseous) or vomit. Let your treatment team know if you feel nauseous, as they may be able to offer another anti-nausea medicine.

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

Targeted therapy

New types of drugs known as targeted therapy target specific mutations within cancer cells. These drugs can be highly effective, but they will only work if the cancer contains the particular target, and even then, they do not work for everyone.

Targeted therapy is currently available for the most common gene mutations associated with non-small cell lung cancer (NSCLC) – see page 19. Approved drugs include afatinib, alectinib, ceritinib, crizotinib, erlotinib and gefitinib. At this stage, targeted therapy drugs are generally available only for NSCLC that is advanced or has come back. Targeted therapy drugs for small cell lung cancer are being tested in clinical trials (see page 26).

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 for more information about new drug trials.

Cancer cells often become resistant to targeted therapy drugs over time. If the first-line treatment stops working, your oncologist

will suggest trying another targeted therapy drug. This is known as second-line treatment.

Side effects of targeted therapy

Although targeted therapy drugs cause fewer side effects compared with standard chemotherapy drugs, they can still have side effects. These vary depending on the targeted therapy drugs used – some may cause an acne-like rash or other skin changes and diarrhoea, others may cause nausea and vomiting or swelling. Less commonly, some targeted therapy drugs affect the way the heart and lungs work, which can be life-threatening, so it's important to report any side effects to your medical team. For a detailed list of side effects for a particular targeted therapy, visit eviq.org.au.

► See our *Understanding Targeted Therapy* fact sheet.

Immunotherapy

Some cancers produce particular proteins, such as PD-1 or PD-L1, that stop immune cells from recognising and destroying the cancer cells. Immunotherapy drugs known as checkpoint inhibitors block these proteins. Once the proteins are blocked, the immune cells can attack the cancer.

Checkpoint inhibitors that have been approved for some types of advanced NSCLC include atezolizumab, durvalumab, nivolumab and pembrolizumab. Several other checkpoint inhibitors are currently being tested in clinical trials for lung cancer. Checkpoint inhibitors do not work for all lung cancers, but some people have had very encouraging results.

Side effects of immunotherapy

Immunotherapy drugs have different side effects to chemotherapy drugs and most people have few if any side effects. However, immunotherapy can cause inflammation in any of the organs in the body and this sometimes leads to side effects such as fatigue, shortness of breath and diarrhoea.

➤ 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 symptoms caused by the cancer, such as pain or breathlessness.

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

Chemotherapy, radiation therapy, surgery and targeted therapy may be used palliatively to slow the spread of cancer and/or control symptoms.

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 the *Managing symptoms* chapter (pages 40–50) for more details.

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

➤ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.



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.

Treatment for early lung cancer

Treatment for early lung cancer may involve:

- surgery – a whole lung, a lobe or part of a lobe may be removed. Effective pain management, gentle breathing exercises as part of a pulmonary rehabilitation program, and being active will help your recovery after surgery
- 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 difficulty swallowing and heartburn, red or dry skin, fatigue, or shortness of breath or 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 or vomiting.

Treatment for advanced lung cancer

The goal of treatment for advanced lung cancer is to slow the spread of the cancer and manage symptoms. Treatment may include:

- chemotherapy and radiation therapy – can relieve symptoms such as pain
- targeted therapy – uses drugs that target specific mutations within cancer cells
- immunotherapy – uses drugs that remove barriers to the immune system attacking the cancer.



Managing symptoms

For many people, lung cancer is diagnosed at an advanced stage. The main goal of treatment will be to manage your symptoms and keep them under control for as long as possible. Treatment can help you feel better and improve quality of life. This is called palliative treatment (see page 38).

This chapter describes treatments and strategies for managing the most common symptoms of lung cancer. As you may be experiencing a number of symptoms, you may have a combination of treatments. Keep in mind, however, that you won't necessarily experience every symptom listed here.

Breathlessness

Many people with lung cancer have difficulty breathing and shortness of breath (dyspnoea). This can be challenging and may cause distress.

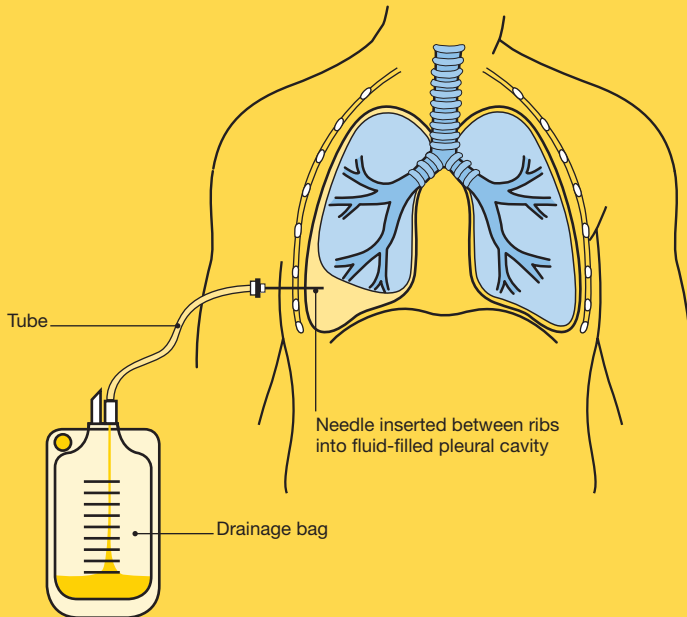
Types of surgery that can help improve this symptom include a pleural tap to drain the fluid (see opposite), pleurodesis to stop fluid building up again (see page 42) and an indwelling pleural catheter (see page 43). You may have one or more of these procedures to ease symptoms even before lung cancer is diagnosed, and they could be suggested at any time to improve breathlessness.

You may also be referred to a pulmonary rehabilitation course to learn about how to manage breathlessness, which will include exercise training, breathing techniques 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 (pleural cavity). This is called pleural effusion and can put pressure on the lung, making it hard to breathe. 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 don't usually have to stay overnight 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/living-with-a-lung-disease/lung-cancer 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 your preferences:

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 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.

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, talcum powder mixed with salt water (a "slurry") is injected through the tube into the pleural cavity. To help distribute

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.

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.

Using local anaesthetic, the doctor inserts the catheter through the chest wall into the pleural cavity. One end of the tube remains inside the chest, and a small length remains outside the body for drainage. This end is coiled and tucked under a small dressing.

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. Your family or a 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 and treatments 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 in a chair

Use a recliner chair to help you sleep in a more upright position.

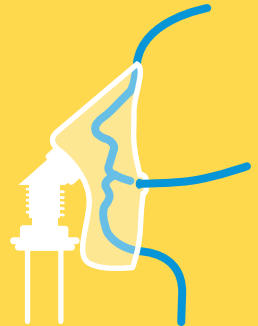


Ask about medicines

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

Check if equipment could help

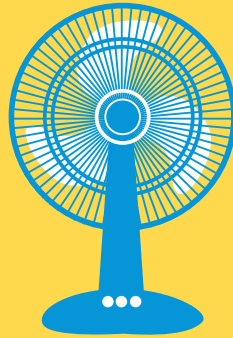
Ask your health care team about equipment to manage breathlessness. To improve the capacity of your lungs, you can blow into a device called an incentive spirometer. You may be able to use an oxygen concentrator at home to deliver oxygen to your lungs, or a portable oxygen cylinder for outings. If you 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 and/or occupational therapist from your treatment centre can explain how to modify your activities to improve breathlessness.



Create a breeze

Use a fan to direct a stream of air across your face if you feel short of breath. 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 or online. Some people find breathing exercises, acupuncture and meditation helpful. Call **13 11 20** for a copy of *Understanding Complementary Therapies*, or find it on your local Cancer Council website.



Pain

Pain can be a symptom of lung cancer, but can also be a side effect of treatment such as surgery or chemotherapy. Medicines to control pain may be mild, like paracetamol; moderate, like codeine; or strong and opioid-based, like morphine. Various procedures can manage fluid build-up that is causing pain (see pages 40–43). Radiation therapy (pages 31–34) and chemotherapy (pages 34–36) can shrink a lung tumour that is causing pain or can relieve pain from cancer that has spread to the bones.

Tell your team if you are in pain. 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/morphine and for the 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 or online.
- See our *Overcoming Cancer Pain* booklet and listen to our podcast episode on pain.

Poor appetite and weight loss

Some people stop feeling interested in eating and lose weight even before lung cancer is diagnosed. These symptoms may be caused by the disease itself, or by nausea, difficulty swallowing, breathlessness, 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. You may find it useful to talk to a dietitian who is experienced in treating people with cancer. A dietitian can help you find foods that you can manage, and can recommend protein drinks and other supplements if needed. You can ask your treatment team to refer you to a dietitian.



Eating when you have little appetite

- Have small meals and snacks regularly. A large, full plate may put you off eating – try using a smaller plate with moderate portions instead. Likewise, drink from a half-full glass.
 - 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 nauseous.
 - Avoid fatty or sugary foods if these make you feel sick.
 - Use lemon juice and herbs to add flavour to bland food.
 - Add ice-cream or fruit to a drink to increase kilojoules and nutrients.
 - 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 the side effects of drugs, and can 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. Even a gentle walk around the garden or block can boost your energy levels.
- Ask for and accept offers of help with tasks such as shopping, cleaning and gardening.
- Eat nutritious food to keep your energy levels up.
- Consider acupuncture – some find it helps with fatigue.
- ▶ Listen to the “Managing Cancer Fatigue” episode of our podcast.

Difficulty sleeping

Getting a good night's sleep is important for maintaining your energy levels, reducing fatigue, and improving mood. Difficulty sleeping may be caused by pain, breathlessness, anxiety or depression. Some medicines can also disrupt sleep. If you already had sleep problems before the lung cancer diagnosis, these can become worse.

Talk to your doctor about what might be helpful for you. Your medicines may need adjusting or sleep medicines may be an option. There are also a number of strategies that other people with cancer have found helpful (see below).



Getting a better night's sleep

- Try to do some gentle physical activity every day. This will help you sleep better. Talk to a physiotherapist or exercise physiologist, who can tailor an exercise program, and an occupational therapist, who can suggest equipment to help you move safely. You can also read our *Exercise for People Living with Cancer* booklet or call **13 11 20** to find out about exercise programs.
- Limit or cut out the use of alcohol, caffeine, nicotine and spicy food.
- Avoid using technology, such as television, computers or smartphones, before bed, as the 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.
- Try listening to gentle music, a recording of rain sounds, or a relaxation recording.
- 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, breathing techniques and pacing tips
- self-management – such as sleeping upright, gentle exercise, using a fan, positioning pillows and relaxation techniques.

Pain

Pain can be managed with:

- pain medicines – mild (e.g. paracetamol), moderate (e.g. codeine) or strong (e.g. morphine)
- 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
- difficulty sleeping – try to do some gentle physical activity every day and set up a regular bedtime routine.



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 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 help you connect with other people with a similar diagnosis, and provide you with information about managing the emotional and practical impacts (see page 56).

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

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 affected by 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 **beyondblue** on **1300 224 636** 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 monitor your health. 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.

If your treatment has finished, follow-up appointments may be 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 find that they think more about the cancer and may 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 following diagnosis. This is why it's important to have regular check-ups.

If the cancer returns, your doctor will discuss the treatment options with you. These will depend on the type of lung cancer and where the cancer has recurred, as well as the stage and grade of the cancer. You may be offered radiation therapy, chemotherapy or the option to join a clinical trial. If you have recurrent non-small cell lung cancer, you may also be offered targeted therapy.



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 Australia	canceraustralia.gov.au
Cancer Council Online Community	cancercouncil.com.au/OC
Optimal Care Pathways	cancerpathways.org.au
<i>The Thing About Cancer</i> podcast	cancercouncil.com.au/podcasts
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
Department of Health	health.gov.au
Department of Human Services (includes Medicare and Centrelink)	humanservices.gov.au
Healthdirect Australia	healthdirect.gov.au
Palliative Care Australia	palliativecare.org.au
Quitline	quitnow.gov.au
Lung Foundation Australia	lungfoundation.com.au
Radiation Oncology: Targeting Cancer	targetingcancer.com.au
International	
American Cancer Society	cancer.org
Macmillan Cancer Support (UK)	macmillan.org.uk
Cancer Research UK	cancerresearchuk.org



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with 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 works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or 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

ablation

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

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

alveoli

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

anaesthetic

A drug that stops a person feeling pain during a medical procedure. 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 fibres. Once used in building but now banned in Australia because the fibres can cause serious illness.

benign

Not cancerous or malignant.

biopsy

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

bronchioles

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

capillary

The smallest type of blood vessel in the body.

catheter

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

cells

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

chemoradiation

Treatment that combines chemotherapy with radiation therapy. Also known as chemoradiotherapy.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

core biopsy

A procedure in which a tissue sample is removed from an organ or lymph node using a wide needle.

CT scan

Computerised tomography scan. This scan uses x-rays to create a detailed cross-sectional picture of the body.

diaphragm

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

emphysema

A non-cancerous condition in which the alveoli of the lungs are enlarged and damaged, usually due to smoking. It causes breathing difficulties.

endobronchial ultrasound (EBUS)

A type of bronchoscopy that uses a flexible tube with a small ultrasound probe to examine the airways and lungs and take tissue samples.

genes

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

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.

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.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess

fluid from tissues, absorbs fatty acids, transports fat and produces immune cells. Includes spleen and lymph nodes.

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.

mesothelioma

Cancer affecting the protective covering that surrounds some of the body's internal organs (the mesothelium). See pleural mesothelioma.

metastasis (plural: metastases)

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

MRI scan

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

mutation

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

oesophagus

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

palliative treatment

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

parietal layer

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

PET scan

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

pleura

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

pleural cavity (pleural space)

The space between the pleural layers; 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 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.

prognosis

The expected outcome of a person's disease.

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.

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.

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 inspecting the lungs that uses a thoracoscope, a thin tube with a tiny video camera. The thoracoscope is inserted through a small cut in the chest under local or general anaesthetic. See also VATS.

thoracotomy

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

trachea

The windpipe. 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 cancerous) or malignant (cancer).

VATS

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

visceral layer

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

wedge resection

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

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancerivc.org.au/glossary
- cancersa.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.

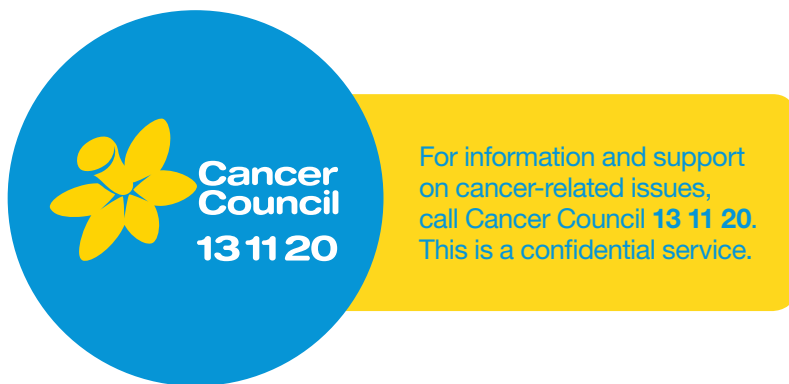
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

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.*