Understanding a lung cancer diagnosis

Receiving a diagnosis of lung cancer can be overwhelming. There is a lot of information that can be difficult to take in but understanding what to expect can help alleviate some of the anxiety. This booklet provides clear and supportive guidance for you as you go through the early stages of diagnosis and treatment.

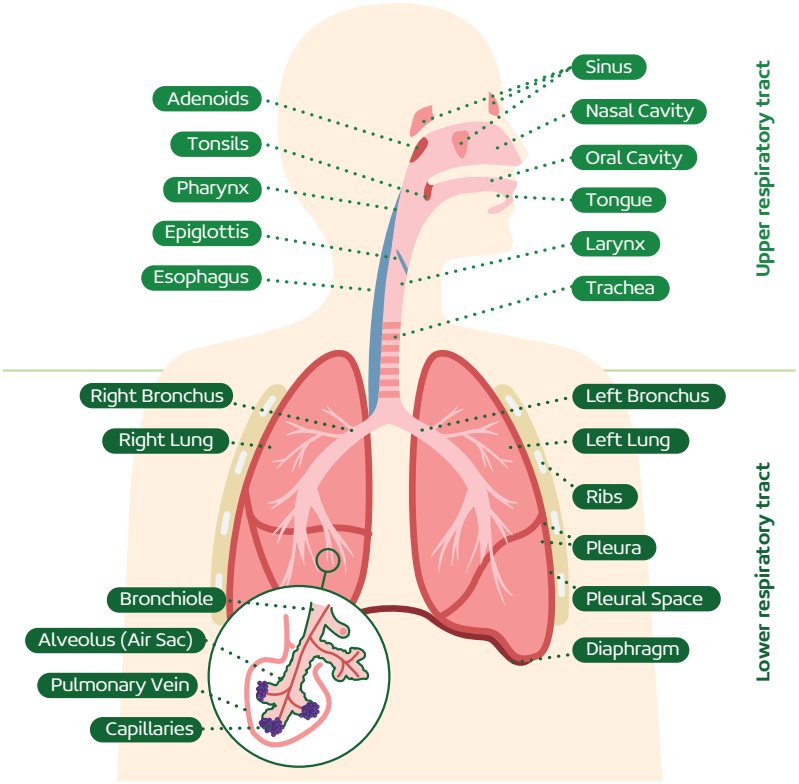
Lung Foundation Australia

Contents

Your lungs

Your lungs are one of your body's main organs. They sit in your chest and form part of your respiratory system, which includes the organs and tissues that allow you to breathe. Your respiratory system is divided into the upper respiratory tract and the lower respiratory tract. Your lungs are part of the lower respiratory tract. Together, they work to make sure your body has enough oxygen and remove other gasses like carbon dioxide from your body.

The respiratory system



Find out more

Trachea	Also known as your windpipe, this is the tube that passes air from your throat to your lungs
Right lung	Made up of three sections called lobes
Left lung	Divided into two lobes
Bronchial tubes	Your trachea divides into two main bronchial tubes, which then further divide into bronchioles. Air sacks, known as alveoli, are located at the end of these tubes. This is where oxygen from the air passes into your blood and carbon dioxide from your body passes back to your lungs to be breathed out
Pleura	A thin membrane with two layers that wraps around the outside of your lungs (the inner layer is called the visceral pleura) and lines your chest wall (the outer layer is called the parietal pleura). The space between the membranes is filled with a small amount of fluid called pleural fluid, which makes it easier for your lungs to move without friction when breathing. This fluid is constantly being produced and drained by your body
Diaphragm	A strong wall of muscle that separates your chest cavity from your abdominal cavity. It is the main muscle responsible for breathing

What happens when you breathe?

Diaphragm contracts (moves down)

Air is pulled in through your nose or mouth

Air moves down through your trachea, into your bronchi, the smaller bronchioles and then into the alveoli

In the alveoli, oxygen and carbon dioxide are exchanged between your blood and your lungs

How are oxygen and carbon dioxide exchanged in the alveoli?

a. The alveoli have very thin walls, so the oxygen in the air can pass through the walls into small blood vessels called capillaries. This is how oxygen from the air is transferred throughout your body

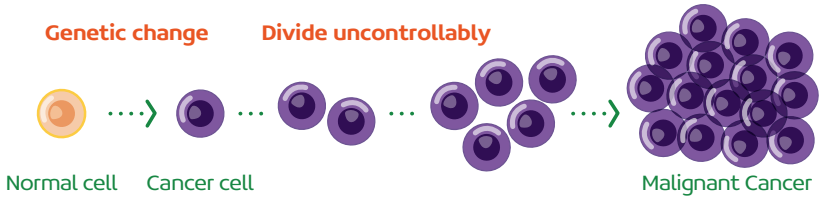
b. At the same time, carbon dioxide is released from your blood cells into the capillaries and then passes back into your lungs where you can breathe it out

What is lung cancer?

Lung cancer is a type of cancer that starts in your lungs – not a cancer that has spread to your lungs (this is called a lung metastasis). It begins when some of your lung cells develop changes in their DNA (called a mutation), causing them to divide uncontrollably. This means that you end up with more and more mutated lung cells (cancer cells), which may form a mass called a tumour.

- A tumour is a collection of cells that form an abnormal mass of tissue. Tumours can be malignant, which means they may spread to other parts of the body, or they can be benign (not cancerous) and typically will not spread

Process of cancer-cell development

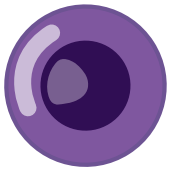


The first cell that mutates – called the cell of origin – determines the type of cancer it becomes. For example, if the cell was originally a flat lining squamous cell, it may lead to squamous cell carcinoma. If it was a glandular cell, it may lead to adenocarcinoma.

In Australia, lung cancer is the fifth most-commonly diagnosed cancer with approximately 14,782 people diagnosed in 2023.

That's more than 40 people diagnosed every day.

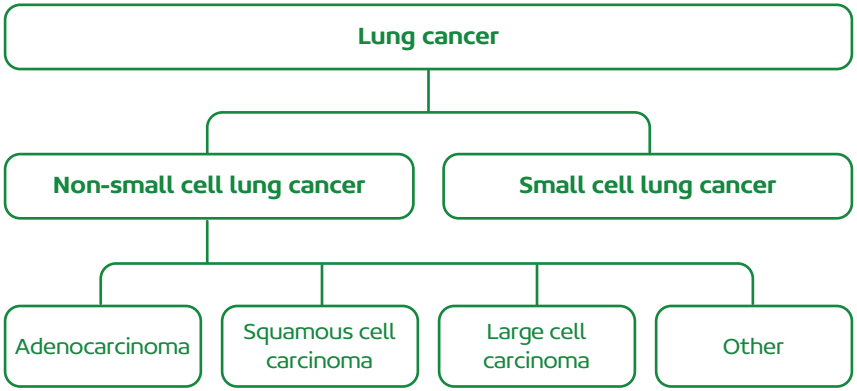
What is the difference between cancer cells and normal cells?



Cancer cells	Normal cells
Grow without any signals from your body telling them to grow	Only grow when they receive a signal
Ignore signals that normally tell cells to die	Die at a set time
Spread into other areas of the body	Stop growing when they encounter other cells and usually do not move around the body
Hide from the immune system	The immune system normally removes any abnormal cells

Types of lung cancer

There are two main types of lung cancer: non-small cell lung cancer or small cell lung cancer. All cancers are different, so it is important to know the type of lung cancer that you have as it will help guide the cancer treatment you receive.



What's the difference between non-small cell and small cell lung cancers?

The difference is based on the size of the individual cancer cells seen under a microscope:

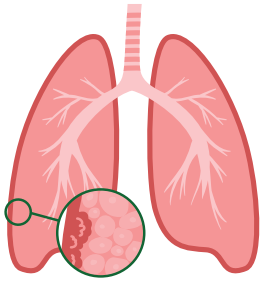
- Small cell lung cancer cells look small and round under a microscope while non-small cell lung cancer cells look larger
- Small cell lung cancer tends to be more aggressive and as such they grow and spread faster than non-small cell lung cancer

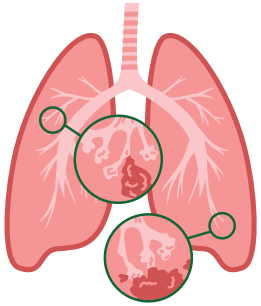
Non-small cell lung cancer

This is the most-common type of lung cancer. It makes up around 85% of all lung cancers. There are three main subtypes of non-small cell lung cancer, which start from different types of lung cells.

Adenocarcinoma

Starts in the cells that make mucus in the outer area of the lung (epithelial cells). It is the most-common type of non-small cell lung cancer occurring primarily in people who smoke or used to smoke. It is, however, also the most-common type of lung cancer in people who do not smoke.



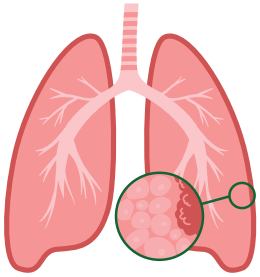


Squamous cell carcinoma

Starts in the cells that line the inside of the airways in the lungs (squamous cells). These cells may be found in large airways in the middle of the chest, or much smaller airways further out.

Large cell carcinoma

Starts in any part of the lung. It tends to grow and spread quicker than adenocarcinoma or squamous cell carcinoma.



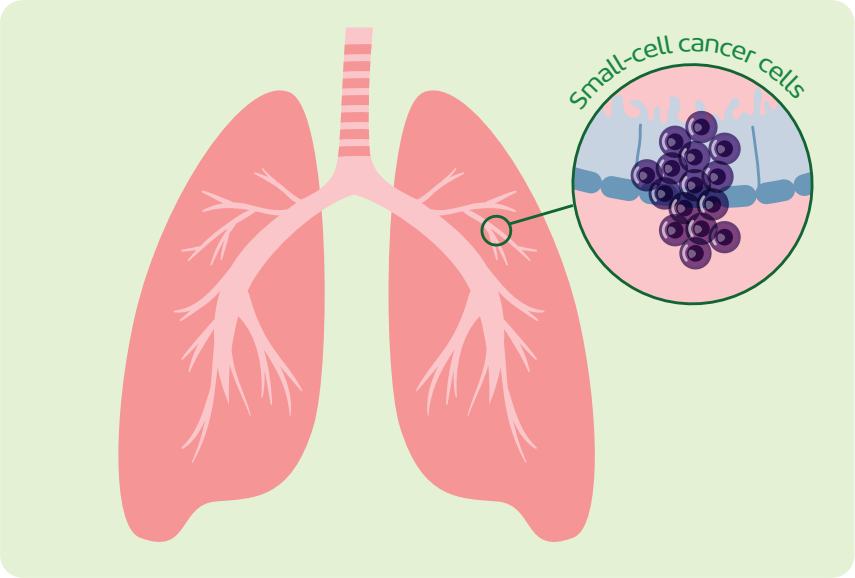
There are some other less-common types of non-small cell lung cancer. Sometimes the cancer is not comprised of one type of cell and can be a mixed pathology, such as:

- Sarcomatoid carcinoma, a mix of carcinoma and sarcoma
- Adenosquamous carcinoma, a mix of squamous cell carcinoma and adenocarcinoma
- NOS, or not otherwise specified, mixed pathology features that do not fit one diagnostic type

Small cell lung cancer

Small cell lung cancer is less common than non-small cell lung cancer, accounting for 11–13% of new diagnoses. It usually starts as a small nodule in the outer area of the lungs. It is a relatively fast-growing type of cancer and it has often spread to lymph nodes and/or other parts of the body by the time it is diagnosed.

Although small cell lung cancer can affect anyone, it occurs primarily in people who smoke or used to smoke.



Risk factors for lung cancer

There are generally two types of risk factors: modifiable risk factors and non-modifiable risk factors.

Modifiable risk factors – risk factors that *can* be changed

Smoking

Smoking is the largest risk factor for lung cancer. People who currently smoke are 9 times more likely to develop lung cancer than someone who has never smoked. People who have previously smoked are almost 4 times more likely to develop lung cancer than someone who has never smoked. Cigarettes, cigars, pipes, menthol cigarettes – even light cigarettes – all increase the risk of lung cancer.

Every single cigarette you smoke increases your risk. The more you smoke and the longer you smoke, the higher your risk of lung cancer. If you quit smoking now, it will reduce your future risk of developing lung cancer – It's never too late to quit.

What about vaping?

Vaping coats your lungs with a range of harmful chemicals that cause damage to your lungs. We don't know yet if vaping causes lung cancer because it has not been around long enough for scientists to determine a clear connection.

Passive smoking

Passive smoking, or second-hand smoke, can increase your risk of lung cancer. Even if you don't smoke but you are frequently around people who do smoke, such as at work or at home, your risk of lung cancer increases. The longer you are exposed to second-hand smoke, the higher your risk of developing lung cancer.

Environmental and occupational risk factors

There are some chemicals in the workplace and in the environment that can increase your risk of lung cancer.

- Occupational exposures such as diesel exhaust, silica, asbestos, radon, radioactive ores (for example, uranium) and some chemicals (including arsenic, beryllium, cadmium, vinyl chloride, nickel compounds, chromium compounds, coal products, mustard gas and chloromethyl ethers)
- Exposure to air pollution in the environment such as industrial emissions, vehicular exhaust and particulate matter

You can find out more information about these occupational hazards by searching for lung cancer at **Safe Work Australia**

Non-modifiable risk factors – risk factors that *cannot* be changed

Family history of lung cancer

Genetics can influence your risk of developing lung cancer. If a close relative has had lung cancer, your own risk may be increased.

Previous radiation therapy to the lungs

If you have previously received radiation therapy targeting your lung area, for example, for the treatment of lymphoma or breast cancer, your risk of developing lung cancer may be increased. This risk increases significantly if you smoke.

Older age

Lung cancer is most-commonly diagnosed in people who are aged 60 years and older.

Having one or more risk factors, doesn't guarantee that you will develop lung cancer. And some people with lung cancer may not have any known risk factors.

Symptoms of lung cancer

The symptoms you experience are different for everyone.

- Early-stage lung cancer often doesn't have any symptoms and may be detected through other routine investigations
- Some people may have symptoms because of where the tumour is located, for example, if the tumour is near an airway, you may have a cough, or if it is blocking an airway, you may develop an infection

If you do experience symptoms, you may have one or several different types. Many of these symptoms are not specific to lung cancer and could relate to a range of other conditions.

Lung symptoms

- Cough that doesn't go away after a few weeks or gets worse
- Hoarseness
- Pain in the chest or shoulder
- Trouble breathing (shortness of breath, feeling unable to take a deep breath)
- Wheezing (high-pitched whistling sound while breathing)
- Coughing up blood – even in small amounts

General symptoms

- Loss of appetite
- Unexplained weight loss
- Feeling tired or weak

Symptoms due to the cancer having spread to other parts of the body

- Bone pain, for example, in your hips or back – from spread to your bones
- Swollen lymph nodes, for example, in your neck – from spread to your lymphatic system
- Headache, weakness/numbness in your limbs, dizziness, seizures – from spread to your brain
- Yellowing of your skin or eyes – from spread to your liver

These symptoms alone do not mean that your cancer has spread to these areas, but they should prompt further investigation, so make sure you tell your doctor if you experience any of them.

Tests to diagnose lung cancer

If your doctor suspects you may have lung cancer, they will order several tests to investigate. This may confirm the diagnosis and determine if the cancer has spread beyond your lungs. Because the symptoms of lung cancer may be similar to other more-common illnesses, getting a diagnosis may involve several steps.

Step 1. Initial tests to see what may be wrong

- **Blood tests:** Help rule out any other causes, check your levels of electrolytes, how your kidneys and liver are working, your blood count and risk of bleeding. A blood test can't provide a cancer diagnosis on its own
- **Chest X-ray:** Shows your doctor if there is anything that requires further investigation. It may also provide an alternative explanation for symptoms such as infection (in this case, you may need a repeat X-ray following appropriate treatment). Often if the results show something of concern you will also go on to have a CT scan
- **CT scan:** Creates a detailed image of your body. It can detect smaller tumours than an X-ray and can also be used to see if the cancer has spread
  - Non-contrast CT scans have a lower dose of radiation and can be used to look at the tissue in the lungs and any lung nodules while contrast CT scans provide better definition when looking at any structures in the middle of the chest

Step 2. If your doctor thinks further investigation is required

- **PET scan:** PET stands for positron emission tomography. This type of imaging is used to show any cancer in the lungs or if it has spread to other parts of your body. A PET scan is not able to diagnose cancer, but can help identify any cancer spread and the stage of your lung cancer
- **Biopsy:** Involves taking a small sample of tissue or fluid from your lungs to look for cancer cells. This can help determine if it is cancer, and if so, what type of cancer. A biopsy is the only way to confirm a lung cancer diagnosis. There are a range of different techniques that can be used to take a biopsy sample from your lungs
- **Other sampling techniques to check for cancer cells:**
  - Sputum cytology: Mucus from your lungs may be tested for cancer cells, however, this is rarely adequate to provide a diagnosis
  - Aspiration of pleural effusion: If you have fluid around your lungs, it may be tested for cancer cells before a biopsy is taken
- **Lung-function test (spirometry):** Checks to see how well your lungs are working to help see how fit you are for treatment

Types of biopsy

CT-guided lung biopsy: A CT scan will be used to line up the site of the biopsy and ensure that the sample is taken from exactly the right place. You will be given a local anaesthetic or possibly sedated to ensure that you don't feel any pain and then a fine needle will be inserted through your chest into the part of your lung that requires investigation.

Bronchoscopy: While sedated or under a general anaesthetic, a tube with a light and a camera on it (bronchoscope) will be passed through your mouth or nose down into your bronchi. Once there, your doctor will take samples of the cells from the bronchi which can be investigated for cancer. A bronchoscopy is the biopsy technique used to take samples from lymph nodes in the chest.

- **Endobronchial ultrasound (EBUS):** This is a type of bronchoscopy, which includes a bronchoscope with an ultrasound probe attached to the camera. Attaching the ultrasound probe helps to show even deeper parts of the lung
- **Transbronchial needle aspiration (TBNA):** Often used together with an EBUS, a TBNA is used to take tissue samples from areas of the lung that are close to the bronchi. It involves passing a needle through the bronchi to take a sample for analysis

Mediastinoscopy: Takes samples of the lymph nodes in the mediastinum (the area in your chest between your lungs). It involves making a small cut on your throat and passing a tube down the outside of your trachea until it reaches the mediastinum where a sample can be taken.

Thoracoscopy: Using a tube with a light and a camera, a sample can be taken from the lungs, the lymph nodes or the area just outside the lungs – the pleura. It involves making a very small cut on your chest and feeding the tube into the area to take a sample.

During the process of diagnosis, you may also need biopsies of other organs to confirm if the lung cancer has spread to different parts of your body.

Molecular tests for lung cancer

Your doctor may recommend using part of your biopsy sample for a molecular test. If you have lung cancer, a molecular test could help to determine if any biomarkers are present that could help inform your cancer treatment.

What are biomarkers?

Biomarkers are specific genes, proteins or other substances that are in a cancer cell. They may also be called driver mutations or oncogenic drivers.

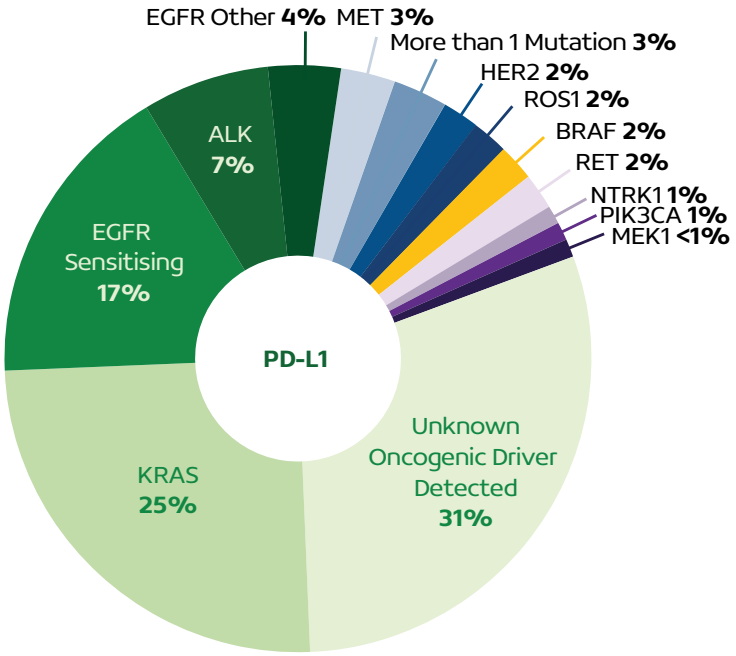
Why test for them? Because not all cancer cells are the same – one person may have different biomarkers to another person with the same type of cancer, which means that their tumour may respond differently to different treatments. Testing for these biomarkers can help your doctor decide what is the most-appropriate treatment for you.

Biomarkers can tell us a lot about your tumour, including:

- How fast it will grow and spread
- Which targeted treatments may work to kill the cancer cells, and which ones won't
- How well a treatment is working

Which biomarkers are relevant in lung cancer?

If you have been diagnosed with lung cancer, you should ask your doctor if your biopsy sample has been tested for biomarkers. Biomarkers are most common in people with adenocarcinoma (a subtype of non-small cell lung cancer).



Adapted from Tsao AS *et al.* Scientific Advances in Lung Cancer. *J Thorac Oncol.* 2015;11(5):613-638.
ALK=anaplastic lymphoma kinase; BRAF=v-raf murine sarcoma viral oncogene homolog B1; EGFR=epidermal growth factor receptor; HER2=human epidermal growth factor receptor 2; KRAS=Kirsten rat sarcoma 2 viral oncogene homolog; MEK1=mitogen-activated protein kinase kinase 1; MET=met proto-oncogene; PIK3CA=phosphatidylinositol-4,5-bisphosphate 3-kinase, catalytic subunit alpha; PD-L1=programmed death-ligand 1; RET=rearranged during transfection; ROS1=ROS proto-oncogene 1; NTRK1=neurotrophic receptor tyrosine kinase 1.

You may also have your levels of PD-L1 tested. PD-L1 is a type of protein found on both healthy and cancerous cells. High levels of PD-L1 on cancer cells may indicate that you may benefit from a specific immunotherapy called immune checkpoint inhibitors (see page 36).

Staging for lung cancer

Part of your diagnosis will include staging your lung cancer, which means finding out how big the cancer is and if it has spread to other parts of your body. After the clinical team has determined what kind of lung cancer you have, they will use the results of the tests you received during diagnosis to determine the stage. Knowing the stage of your lung cancer will help determine what treatment is most appropriate for you.

The tumour-node-metastasis (TNM) system

There are three factors that are used to determine stage known as the TNM system.

- **T:** The extent of the primary tumour
- **N:** Whether and where lymph nodes have cancer cells
- **M:** Whether the cancer has metastasised

Each of these factors are given a value, which is then used to determine your cancer stage.

Stage 0	Early stage	• Located only in the top lining of the lung or bronchus. Has not spread
Stage 1	Early stage	• The cancer has not spread to the lymph nodes or other parts of the body • Divided into two sub-stages, 1A and 1B, based on the size of the tumour
Stage 2	Early stage	• The cancer has not spread to distant organs but may be larger than those in Stage 1 and/or has begun to spread to nearby lymph nodes • Divided into stages 2A and 2B, with each stage then broken into additional sections depending on the size of the tumour, where it is found and whether the cancer has spread to the lymph nodes
Stage 3	Locally advanced	• The cancer has spread to the lymph nodes in the centre of the chest between the heart and lungs (the mediastinum) or has grown into the chest wall or the outer lining that surrounds the heart (the pericardium) • Divided into 3A, 3B or 3C, depending on the size and location of the tumour and how far it has spread
Stage 4	Advanced	• The cancer has spread to the other lung, has been found in fluid around the heart or lung or spread to other parts of the body. This includes distant lymph nodes or to other organs such as the bones, liver and brain

Small cell lung cancer staging

Small cell lung cancer can be staged with the TNM system, or sometimes, it may be staged using a different system in which the tumour is classified as either limited or extensive.

- **Limited disease**: Only located in one lung with/without spread to the lymph nodes in the mediastinum
- **Extensive disease:** Spread to tissue outside the originally affected lung such as the opposite lung or distant organs

Prognosis after a lung cancer diagnosis

Once your treating team has all the information about your cancer and knows what treatment you will start on, they will talk to you about what the future may look like and your prognosis, which means how the disease is expected to progress and what the likely outcomes are.

Clinical trials often talk about 5-year survival and your doctor may give you a 5-year relative survival rate, which tells you how likely it is that someone with lung cancer is alive 5 years after the diagnosis compared with someone without the disease.

- It is important to remember that the numbers your doctor may give you are based upon an average and are not specific to your case

Although it is overwhelming and stressful, this information is important because it can help you to understand what the diagnosis means for you and your future.

Talk to your doctor for more information on your prognosis

The multidisciplinary team

When you are diagnosed, your case may be reviewed by a group of expert healthcare professionals who all specialise in a different aspect of your care – this is called a multidisciplinary team. Together they will help develop a treatment plan specifically tailored to you and your personal preferences so that you can receive the most-appropriate treatment, as soon as possible.

Some of the healthcare professionals who may be involved in a lung cancer multidisciplinary team for your diagnosis and treatment

Aim of treatment

Depending on the stage and type of your lung cancer, there are a range of treatment options available. The different lung cancer treatments generally have different treatment goals:

- **Curative intent:** Treatment aims to make the cancer go away – to provide a cure. This is usually only possible with early-stage lung cancer and it depends on your particular cancer and the treatment options that are available
- **Palliative treatment:** If your lung cancer has been diagnosed at a later stage, which is often the case in lung cancer, the aim of treatment may be to control the growth of the cancer – to shrink it or stop it spreading any further. This type of treatment may help to reduce symptoms and improve your quality of life. It may also help extend your life compared to not having treatment
- **Symptom control:** Lung cancer can have a range of symptoms from breathlessness to pain to fatigue. Some of the treatments you receive may be aimed at improving the symptoms you experience to make each day better

When you speak with your doctor, it is important to discuss your treatment goals and whether they are achievable for your type of lung cancer.

Possible treatment options

Your doctor will tell you about a range of different treatments that are available for your condition and together, you will come up with a plan for treatment. When deciding, it is important that you understand what the treatment does and any side effects you may experience. This will help you to make an informed decision about what is best for you.

Some of the most-common treatment options for lung cancer include:

Surgery

Radiation therapy

Clinical trials

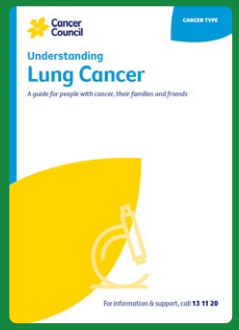
Anticancer drug treatments

- Chemotherapy
- Targeted therapy
- Immunotherapy

You may receive one or several of these treatments either together, known as 'in combination' or before (neoadjuvant) or after (adjuvant) each other. For example:

- Immunotherapy is often given in combination with chemotherapy
- Radiation and chemotherapy are often given either before or after surgery

Managing side effects and symptoms



You can find out more about what side effects to expect from each treatment in the coming pages.

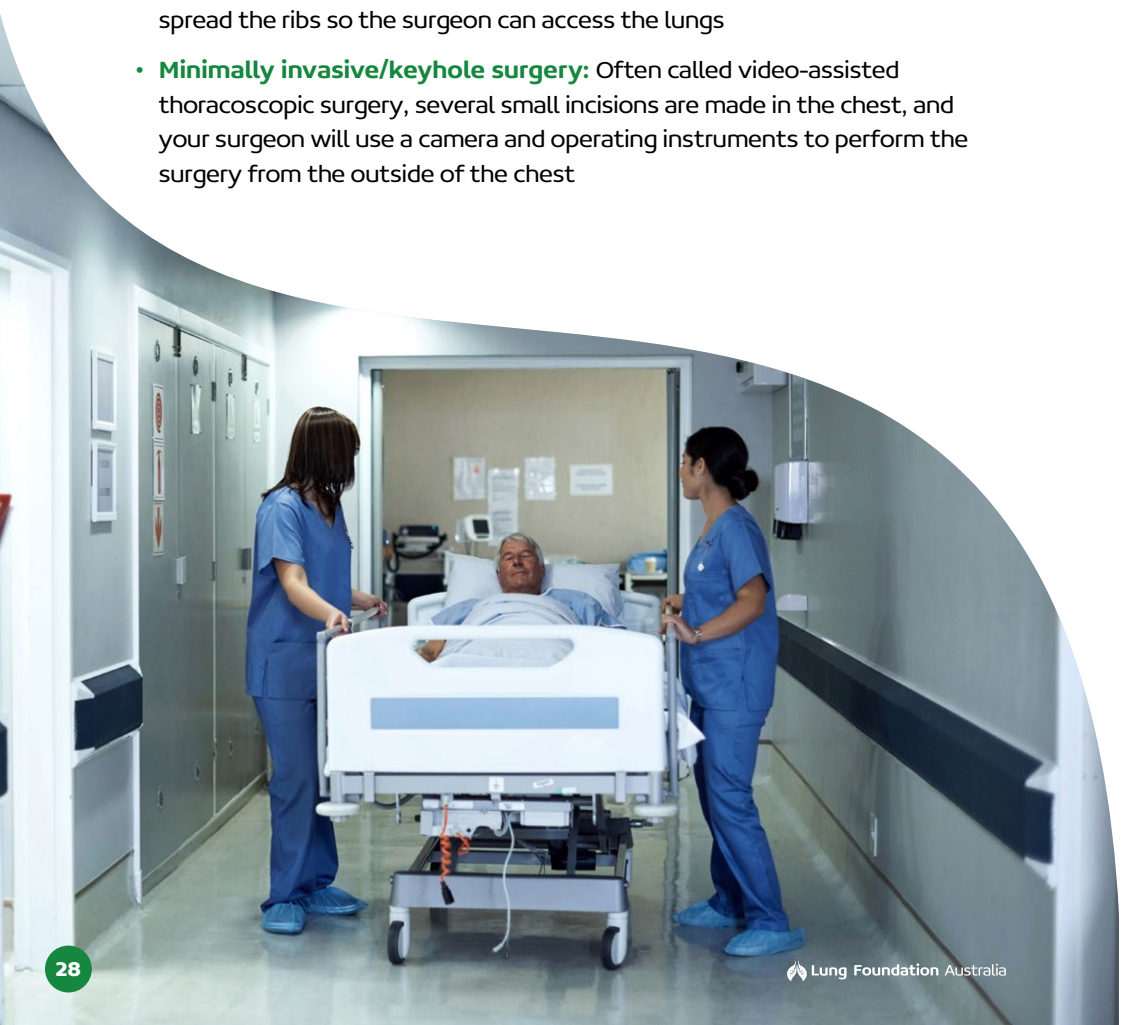
For information on how to manage the side effects with both pharmacological and non-pharmacological treatments, as well as information on managing symptoms with palliative and supportive care, download 'Understanding Lung Cancer' from the Cancer Council.

Surgery

If your lung cancer is in the early stages (stage 1 or 2), you may be offered surgery to remove the tumour, some surrounding lung tissue and sometimes lymph nodes in the region. Surgery is not suitable for everyone, particularly people with late-stage cancers, and your surgeon will consider factors such as if it is possible to remove all of the cancer as well your level of health and fitness to undergo the operation.

Lung surgery will usually be performed either as a thoracotomy or minimally invasive surgery depending on the location, size and stage of the tumour.

- **Thoracotomy:** A cut is made between the ribs and an instrument used to spread the ribs so the surgeon can access the lungs
- **Minimally invasive/keyhole surgery:** Often called video-assisted thoracoscopic surgery, several small incisions are made in the chest, and your surgeon will use a camera and operating instruments to perform the surgery from the outside of the chest



There are four main types of lung surgery. Your surgeon will decide which type of surgery is best for you depending on the size and the location of the cancer.

Wedge resection

Removal of a small, wedge-shaped part of the lung tissue surrounding the tumour.

Mediastinal and hilar nodes sampled during surgery: **No**

Segmentectomy

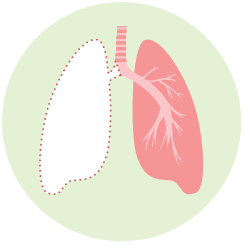
Removal of one or more segments within a lung lobe. This can help to save unaffected tissue.

Mediastinal and hilar nodes sampled during surgery: **May be sampled**

Lobectomy

Involves removing one or more lobes of the lung that are affected by the cancer.

Mediastinal and hilar nodes sampled during surgery: **Yes**



Pneumonectomy

Removal of the entire affected lung.

Mediastinal and hilar nodes sampled during surgery: **Yes**

Following surgical assessment, your surgeon may feel that an operation is not the most-appropriate treatment for you and they may refer you for alternate treatment such as radiation therapy.

Radiation therapy

Radiation therapy uses high-power X-rays to kill cancer cells or keep them from growing. These X-rays are much stronger than those you would receive during an X-ray test. For the treatment of lung cancer, the radiation usually comes from outside the body (called an external beam) from a machine called a linear accelerator as either standard external beam radiation therapy or stereotactic radiation therapy.

- Standard external beam radiotherapy is delivered as a daily treatment over several weeks
- Stereotactic radiation therapy is a highly precise form of radiotherapy delivering larger doses per session and requiring fewer treatments. It is usually used to treat small lung tumours

When can you have radiation therapy?

When you receive radiation therapy depends on the stage of your lung cancer and the goal of treatment. Your doctor may use radiation therapy:

On its own as a curative-intent alternative to surgery

Before surgery to shrink the tumour

After surgery to kill any cancer cells that have been left in the lungs

After chemotherapy or at the same time as chemotherapy

To relieve symptoms such as pain or breathlessness

As disease control for any cancer that has spread outside of the chest

Side effects of radiation therapy

You won't feel anything during the radiation therapy, however, there may be some side effects afterwards. The early side effects of radiation therapy vary depending on where the radiation beam is aimed, but may include:

- Skin changes in the area of radiation
- Nausea and vomiting
- Tiredness
- Sore throat and painful swallowing
- Cough

Radiation therapy may also be associated with delayed side effects – side effects that occur months or years after radiation therapy. These side effects are rare, but may include:

- Breathing difficulties
- Lung fibrosis (scarring and thickening of the tissue in the lung)
- Arm weakness or numbness
- Spinal cord damage
- Secondary cancer (a new primary cancer in someone who has already had cancer)

If you experience any side effects, or they worry you, make sure you discuss them with your doctor.

Anticancer drug treatments: Chemotherapy

Chemotherapy is a cancer treatment that uses drugs to destroy cancer cells in the body. It works by killing cells that rapidly divide, like your cancer cells. Chemotherapy works throughout your whole body, which means that it can also kill any cancer cells that have spread away from your lungs.

You may receive one chemotherapy drug, or a combination of them depending on the type and stage of lung cancer you have. Some common chemotherapy drugs include cisplatin, carboplatin, paclitaxel, docetaxel, gemcitabine or vinorelbine.

Chemotherapy may be given:

- Orally (as a tablet, capsule or liquid)
- Intravenously by a needle into your vein
- As an injection subcutaneously (just under the skin) or into your muscle

When can you have chemotherapy?

Chemotherapy can be used at multiple points during treatment to shrink the tumour or keep it from growing any larger, to kill cancer cells, or to alleviate some lung cancer symptoms. For lung cancer, it can be used:

As the main treatment

With surgery (given before or after)

With radiation therapy

In combination with immunotherapy

Side effects of chemotherapy

Chemotherapy kills all rapidly dividing cells, which includes cancer cells but also healthy cells such as new blood cells in bone marrow or some cells in your mouth, stomach, skin, hair or reproductive organs. When healthy cells are damaged or killed, you may experience temporary side effects. Unlike cancer cells though, these healthy cells can repair themselves. Everyone is different, so you may experience a lot of side effects or only a few.

Some of the most-common side effects include:

- Nausea or vomiting
- Diarrhoea or constipation
- Loss of appetite
- Weight loss
- Fatigue
- Increased risk of an infection
- Bleeding and bruising easily
- Hair loss

Your doctor and pharmacist will talk to you about the possible side effects and how you can manage them. If there are any side effects that you are not sure about or that worry you, make sure you speak with your doctor or pharmacist.

Anticancer drug treatments: Targeted therapy

Targeted therapies are medications that target specific molecules, known as molecular targets. These targets are usually genes or proteins involved in the growth, progression and spread of cancer. Targeted therapies are only suitable if your tumour has a particular mutation. In Australia, some targeted therapies are reimbursed by the Pharmaceutical Benefits Scheme for lung cancer. This list is growing all the time, but currently treatment is reimbursed for lung cancer with the following biomarkers:

- EGFR
- ALK
- ROS1
- MET

Targeted therapies are also available for many other different mutations. Your doctor will talk to you about how you can access them (for example, through a clinical trial) if they are suitable for you.

Treatments that target specific mutations are usually called 'gene name' inhibitors. For example, EGFR inhibitor, ALK inhibitor, ROS1 inhibitor or MET inhibitor etc.

When can you have targeted therapies?

If you received a molecular test during your diagnosis that showed that your tumour had a targetable mutation (see page 20), you may be able to receive targeted therapy. Generally though, targeted therapies may be given throughout the progression of lung cancer:

Early stage

Advanced stage

Lung cancer that has recurred after initial treatment

Targeted therapies are not currently available for small cell lung cancer.

Side effects of targeted therapy

Even though targeted therapy is designed to damage cancer cells without harming normal cells (not targeted at all rapidly dividing cells like chemotherapy), you may still experience side effects. The specific side effects depend on which targeted therapy you receive and they also vary from person to person with some people experiencing none or limited side effects, while others may have several.

Some of the more-common side effects include:

- **EGFR inhibitors:** Skin problems, nail changes, fatigue, loss of appetite, nausea, vomiting and diarrhoea
- **ALK inhibitors:** Vision changes, nausea, vomiting, diarrhoea, swelling in hands and/or feet, tiredness, muscle soreness, nerve damage (peripheral neuropathy) and changes in laboratory values
- **ROS1 inhibitors:** Vision changes, muscle soreness, swelling in hands and/or feet, nerve damage (called peripheral neuropathy), diarrhoea, fatigue and changes in laboratory values
- **MET inhibitors:** Nausea, vomiting, diarrhoea, tiredness, swelling in hands and/or feet, muscle and joint pain, low blood cell counts or changes in other blood tests

Your doctor and pharmacist will talk to you about the possible side effects and how you can manage them. Some side effects can be serious, so make sure you speak with your doctor or pharmacist.

Anticancer drug treatments: Immunotherapy

Immunotherapy drugs use your own immune system to help kill cancer cells. Immunotherapy changes how the immune system works and helps it to find and attack cancer cells. In lung cancer, checkpoint inhibitors are the primary type of immunotherapy available – they work by specifically attaching to cancer cells, flagging them for your own immune system to destroy. Checkpoint inhibitors do this by targeting either a receptor or protein known as PD-L1.

When can you have immunotherapy?

Immunotherapy can be suitable for people with non-small cell lung cancer as well as small cell lung cancer. Your doctor will talk to you about what role it plays in your treatment plan, but you may receive:

Immunotherapy alone

In combination with chemotherapy

After chemotherapy/radiation therapy

In some cases, immunotherapy may not be suitable. For example, if you have an autoimmune disease, have previously had a solid organ transplant or if you have had autoimmune complications associated with immunotherapy before. Talk to your doctor for more information.

Side effects of immunotherapy

Immunotherapy, including with checkpoint inhibitors, can sometimes make your immune system overactive causing it to attack healthy cells as well as cancer cells. This causes side effects known as immune-related adverse events. These side effects vary for everyone: Some people may experience very few side effects, while others may experience several. The most-common side effects include:

- Fatigue
- Cough
- Shortness of breath
- Rash
- Nausea
- Loss of appetite
- Diarrhoea
- Bone or muscle pain

Your doctor and pharmacist will talk to you about the possible side effects and how you can manage them. Some side effects can be serious, so make sure you speak with your doctor or pharmacist.

Clinical trials

Research into the treatment of lung cancer is rapidly changing. New treatments are constantly being developed that may be effective for a range of different conditions. Clinical trials are research investigations to test how well a newly developed treatment works and any side effects it may have. A clinical trial may also help determine how the new treatments work compared with current, existing treatments.

Benefits of a clinical trial

- Access new treatments that are not yet available in Australia
- Gain a better understanding of your type of lung cancer
- Help others who may have lung cancer in the future
- Play a more-active role in your own healthcare
- Receive additional care from the clinical-trial staff

Clinical trials have a set of strict eligibility criteria, so if you are interested, speak with your doctor about any trials that may be suitable for you.

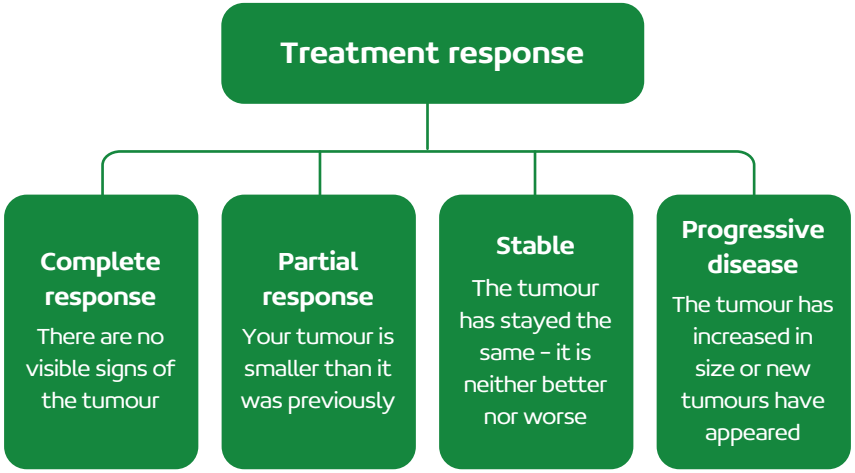
Treatment monitoring – is your treatment working?

During treatment

It is important to know how your tumour is responding to the treatment – is the tumour getting bigger, smaller or staying the same. If you have received surgery, your doctor will give you the results in your follow-up appointment. This can help you and your doctor decide if any changes are required to your treatment plan and what to do going forward.

Treatment monitoring includes some tests every couple of months to assess your treatment response. The tests may include imaging of the inside of your body taken by CT, MRI or PET scan to show how your tumour has changed since your treatment started.

After the tests, your doctor will be able to tell you how you are responding to the treatment.



Post-treatment follow up

You will continue to have regular appointments with your treating team to manage any long-term side effects, check that the cancer has not spread or come back and to discuss your general wellbeing. Living well with lung cancer is an important part of treatment monitoring, so make sure you speak with your doctor about anything that worries you, including your mental health.

How often you have follow-up appointments will depend on the type of cancer you have and the treatment you have received.

It is also important to continue follow-up appointments with your GP as well to ensure that any other underlying health troubles are addressed appropriately. Not all current or future health troubles or symptoms are related to your lung cancer and associated treatment.

After completion of a curative treatment

Even if you have received treatment with a curative intent, for example, surgery, and have had a complete response, you will continue to be monitored even after your treatment has stopped or the surgery has been completed. Monitoring may include both physical examinations and imaging to check if the cancer has come back. You can expect to be monitored:

- Every 6 months for the first 2 years
- Annually after the first 2 years

This schedule will vary depending on you and the type of lung cancer you had.

Who can you speak to for support?

Your doctors and nurses

Your treating team are there to support you throughout your diagnosis and treatment.

- **Experiencing symptoms:** They can refer you to allied health professionals such as physiotherapists, dieticians, speech pathologists or palliative care specialists
- **Struggling emotionally:** They can refer you to psychologists or counsellors
- **Experiencing financial issues:** They can put you in touch with a social worker

Your general practitioner

Your GP is a really important member of your healthcare team even after you have received a diagnosis of lung cancer.

- **Struggling to manage your healthcare appointments:** They can create a GP Management Plan to help coordinate your care across all healthcare professionals and reduce the need for multiple unscheduled consultations or unnecessary hospitalisations
- **Struggling with your mental health:** They can create a GP Mental Health Treatment Plan to give you access to up to 10 individual sessions of mental-health treatment each calendar year to help you feel more in control of your mental health

Find out more about the **Mental Health Treatment Plan** here

Lung Foundation Australia

Lung Foundation Australia is the only charity and leading peak body of its kind in Australia that funds life-changing research and delivers support services that give hope to people living with lung disease or lung cancer. They are here to support you.

More information on lung cancer

Lung Cancer Specialist Nurse is a free service run by highly experienced oncology nurses who can provide evidence-based information regarding diagnosis, treatment and symptoms. This is a telephone-based service for patients, families and carers.

Feel like you are alone

Peer-support programs and groups can help you connect with others who share a similar lived experience. Programs include online, face-to-face or telephone support groups for people with lung cancer.

Help managing the impact of lung cancer

Lung Cancer Social Worker is available via a free telephone-based service for people living with lung cancer, and their family and carers. The experienced social worker can help you to navigate the practical and emotional impact of your diagnosis.

Struggling with breathlessness

Pulmonary rehabilitation can help improve breathlessness and overall quality of life. Lung Foundation Australia can help you find a program that is suitable for you.

Have other respiratory conditions

Respiratory Care Nurse telephone service is available for people who have other underlying respiratory conditions such as COPD or bronchiectasis. The highly skilled nurse can provide guidance on all aspects of your condition according to the management guidelines.

Other useful websites

There is unlimited information online about the diagnosis and treatment of lung cancer, but sometimes it can be hard to tell the difference between a website that is reliable and one that is not. So, if you are looking for information online, here are a few websites that you can trust.

Local Australian websites

Lung Foundation Australia lungfoundation.com.au	**Guides to Best Cancer Care** cancer.org.au/cancercareguides
Cancer Council Australia cancer.org.au	**Cancer Australia** canceraustralia.gov.au
Australian Clinical Trials australianclinicaltrials.gov.au	**Carers Australia** carersaustralia.com.au
Carer Gateway carergateway.gov.au	**Department of Health and Aged Care** health.gov.au
eviQ Cancer Treatments Online eviq.org.au	**Palliative Care Australia** palliativecare.org.au
Healthdirect Australia healthdirect.gov.au	**Services Australia** (including Centrelink and Medicare) servicesaustralia.gov.au
Radiation Oncology: Targeting Cancer targetingcancer.com.au	**National lung cancer screening program** https://www.health.gov.au/our-work/nlcsp
Thoracic Oncology Group Australasia thoraciconcology.org.au	

International websites

American Cancer Society cancer.org	**Cancer Research UK** cancerresearchuk.org
Macmillan Cancer Support (UK) macmillan.org.uk	**National Cancer Institute** https://www.cancer.gov/types/lung

Glossary of useful terms related to lung cancer

A	
Adenocarcinoma	A form of non-small cell lung cancer often found in an outer area of the lung. It develops in the mucus-producing cells that form part of the lining of the lungs
Adjuvant therapy	Treatment given after the main type of treatment (usually surgery) to increase the chances of cure
Advanced cancer	Cancer that is unlikely to be cured. The cancer has usually spread to other parts of the body. Treatment can often still control the cancer and manage symptoms
Alveoli	Very small air sacs at the end of each bronchiole. Here, oxygen enters the blood and carbon dioxide leaves it
B	
Benign	Not cancerous or malignant
Biomarker	A molecule found in the body that is a sign of a normal or abnormal process, or of a condition or disease. Biomarker testing can provide important information about treatment options, particularly in non-small cell lung cancer
Biopsy	The removal a sample of cells or tissue for laboratory examination
Breathlessness	The sensation of shortness of breath or difficulty breathing. Also called dyspnoea
Bronchioles	The smallest airways branching off from each bronchus
Bronchoscopy	A test using a flexible tube with a light (called a bronchoscope) that is passed through the mouth or nose and into the large airways of the lungs to examine the lungs or take samples
Bronchus (plural bronchi)	Either of the two major branches of the trachea that lead to the lungs. The trachea divides to form the right and left main bronchi
C	
Capillaries	Very small blood vessels where oxygen and carbon dioxide are exchanged in the lungs
Complete response	On an imaging scan, the tumour looks like it is completely gone
Cells	The building blocks the human body is made of
Chemoradiation	Treatment that combines chemotherapy with radiation therapy. Also called chemoradiotherapy
Chemotherapy	Drugs that kill cancer cells or slow their growth. May be given alone or in combination with other treatments
CT scan (computed tomography)	A special kind of X-ray that takes many images to create detailed cross-sectional pictures of the body
D	
Diaphragm	The strong wall of muscle that separates the chest cavity from the abdominal cavity and is used to breathe
Dyspnoea	See breathlessness
E	
Endobronchial ultrasound (EBUS)	A type of bronchoscopy that uses a flexible tube with an ultrasound probe to examine the airways and lungs and take tissue samples
External beam radiation therapy (EBRT)	Radiation therapy delivered to the cancer from outside the body
I	
Immune system	A network of vessels and organs that defends the body against attack by foreign invaders, such as bacteria and viruses
Immunotherapy	Drugs that use the body's own immune system to fight cancer
Intravenous (IV)	Injected into a vein

L	
Large cell carcinoma	A type of non-small cell lung cancer that can occur in any part of the lung and tends to grow and spread faster than adenocarcinoma or squamous cell carcinoma. It is characterised by large, rounded cells
Lobe	Sections of the lung. The right lung is divided into three lobes, the left lung is divided into two lobes
Lobectomy	A type of surgery in which a lobe of the lung is removed
Lymph nodes	Small kidney-bean-shaped organs that are distributed all over the body and form part of the immune system
M	
Malignant	Cancerous cells or tumours. Malignant cells are abnormal and grow uncontrollably
Mediastinoscopy	A surgical procedure to let the surgeon look at and take samples of lymph nodes in the area between the lungs (see mediastinum)
Mediastinum	The area in the chest between the lungs. It contains the heart and large blood vessels, the oesophagus, the trachea and many lymph nodes
Metastasis	The spread of cancer from its primary site to other places in the body
Molecular test	A specific test for changes in genes involved in cancer
Monoclonal antibodies	Immune-system proteins that are made in a laboratory and can attach to tumour cells and tell the cell what to do. May be considered as targeted therapy or immunotherapy
MRI scan (magnetic resonance imaging)	Uses magnetic fields and radio waves to create detailed pictures of soft tissues in the body
Mutation	A permanent change in the DNA sequence of a gene

N	
Neoadjuvant therapy	Anti-cancer treatment given before the main type of treatment to increase the chances of treatment success
Non-small cell lung cancer	One of the two main types of lung cancer. It has three main subtypes adenocarcinoma, squamous cell carcinoma and large cell carcinoma
P	
Palliative care	Care aimed at improving quality of life through the management of pain and symptoms
Partial response	The tumour has shrunk in size
Pathologist	A doctor who identifies diseases by studying cells and tissues under a microscope.
PET scan (positron emission tomography)	A radioactive solution is injected into the blood to highlight any cancer cells
Pleura	The mesothelium (thin sheet of tissue) that surrounds each lobe of the lung and separate the lungs from the chest wall
Pleural cavity (pleural space)	The space between the layers of the pleura. It typically contains a thin film of fluid
Pneumonectomy	Surgical procedure to remove the entire lung affected by cancer
Pleural effusion	Excess fluid between the layers of tissue that cover the lungs (see pleura)
Prognosis	A prediction of the probable course and outcome of a disease
Progressive disease	The tumour continues to grow despite treatment
Primary cancer	The original cancer. Cancerous cells from the primary cancer may spread to other parts of the body (see metastasis)

R	
Radiation therapy	A type of therapy using X-ray beams to kill or damage cancer cells so they cannot grow, multiply or spread
S	
Small cell lung cancer	One of the two main types of lung cancer. It often starts as a small nodule in the outer area of the lungs and spreads early in the disease
Sputum cytology	A sample of mucus from the lungs is examined under a microscope to see if cancer cells are present
Squamous cell carcinoma	A form of non-small cell lung cancer that starts in the squamous cells (flat cells found on the surface of the skin or the lining of certain organs)
Stable disease	The tumour does not change in size
T	
Targeted therapy	Drugs that target specific features of cancer cells to stop the tumour from growing
Transbronchial needle aspiration (TBNA)	A test that takes tissue samples from areas of the lung that are close to the bronchi
Thoracoscopy	A test in which a small cut is made in the chest and a thin tube with a light and camera are inserted to look at the space between the lungs and the chest wall
Thoracotomy	A type of surgery in which an incision is made across the back and side of the chest. The ribs are spread apart so the surgeon can access the lung
Trachea (windpipe)	The airway that brings air inhaled from the nose and mouth into the lungs
Tumour	A tumour is an abnormal growth of cells in the body

V	
Video-assisted thoracoscopic surgery (VATS)	A type of keyhole surgery that allows surgeons to make very small incisions to view the inside of the chest cavity and remove cancer
Visceral pleura	The inner layer of the pleura that is attached to the lungs
W	
Wedge resection	Surgery to remove a small portion of the lung along with healthy tissue that surrounds the lung
X	
X-ray	A test to create pictures of the structures inside your body

Notes

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Notes

Lung Foundation Australia Services

- Information and Support Team
- Lung disease information resources
- Education webinars
- Support groups
- Peer-to-peer connections
- Referral to pulmonary rehabilitation and Lungs in Action exercise programs
- E-newsletter

This booklet was developed as a joint effort between a range of healthcare providers and consumers, all of whom dedicated their own time to ensure it provided relevant and informative information for people with lung cancer. Thank you specifically to Simmie Chung, Dr Gerard Olive and Helen Westman for your review and commentary as well as everyone else who contributed.

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