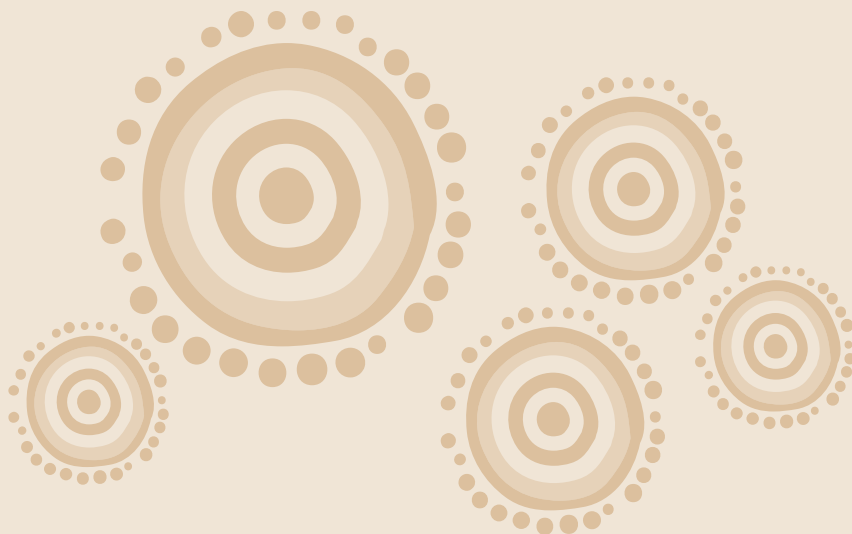




Australian Government
Cancer Australia

MY LUNG CANCER PATHWAY



**A guide for Aboriginal and Torres Strait
Islander people and their families**



My lung cancer pathway...

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My Lung Cancer Pathway: a guide for Aboriginal and Torres Strait Islander people and their families was prepared and produced by Cancer Australia.

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My Lung Cancer Pathway: a guide for Aboriginal and Torres Strait Islander people and their families can be downloaded from the Cancer Australia website: canceraustralia.gov.au or ordered by telephone: 1800 624 973.

1 Diagnosis



Finding out you have lung cancer is called “your diagnosis” and can come as a big shock. Your doctor will help you to understand more about it, how you might be feeling and what will happen next.

How you might be feeling



All these feelings are normal. It can help to speak with someone about how you are feeling.

Your family and community business

Having support from your family and community during your diagnosis and treatment is very important.

Bringing a family member to your appointments with the doctors, nurses or Aboriginal and Torres Strait Islander Health Workers can help them find out more about your diagnosis and treatments, so that they know what is happening and can support you. After your appointments they can also help you talk to other family members, friends and community members by sharing what they heard.

When you are sick, your family, friends and community might find this a stressful and worrying time. That's why it can help if they know what is going on.





Talking to your family

Talking about your cancer with family can sometimes make you feel better and can help you make decisions. You and your family might also like to speak to an Aboriginal and Torres Strait Islander Health Worker or a support person.

Here are some tips you might think about when talking to your family about your diagnosis and how you are feeling:

- think about how much information you would like to share
- be honest and clear when answering their questions
- talk openly with your family about how you are both feeling
- tell them how they can help you.

Who can help you and your family?

	Family, friends or people in your community
	An Aboriginal and Torres Strait Islander Health Worker in your community, your doctor or nurse
	Another person in your community who has had lung cancer or another type of cancer
	Calling the Cancer Council Helpline on 13 11 20 . This is a free, confidential phone information and support service*

*If you need an interpreter, call the Translating and Interpreting Service (TIS) on **13 14 50**.

Your doctor may be a man or a woman. If you would prefer to talk to either a man or a woman about your lung cancer, tell your Aboriginal and Torres Strait Islander Health Worker or nurse.

Talking to your young kids or grandkids

Your kids may feel scared or worried. Decide how much information you think they are ready to hear or know about what is happening. Be honest and talk to them about feelings as well as the facts.



Things that may help	Things that will not help
Talking	Keeping it all a secret
Giving simple answers to questions	Overloading kids with information
Letting kids talk about difficult things	Rushing to reassure, telling kids not to talk about it
Telling kids it is not their fault	Telling kids to 'be good for Mummy or Daddy'
Encouraging kids to work out problems themselves	Trying to fix everything for them
Negotiating tasks	Giving orders
Maintaining routine, rules and consequences	Letting go of structure, rules and discipline because of guilt
Encouraging kids to participate in sport and normal activities	Expecting kids to spend all of their time at home 'because time together is precious'
Allowing others to offer support	Thinking you can do it on your own
Letting the school know	Not letting important people in your kids' lives know, or telling kids to keep everything private
Letting them see that you are upset sometimes	Pretending everything is OK

Things to remember along your pathway

- talking about how you're feeling can help
- ask your local Aboriginal and Torres Strait Islander Health Worker, doctor, nurse or Aboriginal Liaison Officer for more information
- a social worker, counsellor, psychologist, psychiatrist, spiritual guide or religious advisor can help
- your family might like to read this booklet to understand your treatment.

Ask questions

- asking questions is a good way to learn about lung cancer
- you may not always know what the doctor is talking about
- don't be afraid to ask lots of questions.

Below are some sample questions:

- Can you explain this to my family as well?
- Can you write down what you have told me so that I can read it later?
- Can you explain my test results to me?
- Can treatment get rid of the cancer in my body?
- How will this affect my life?

Write your own questions here:

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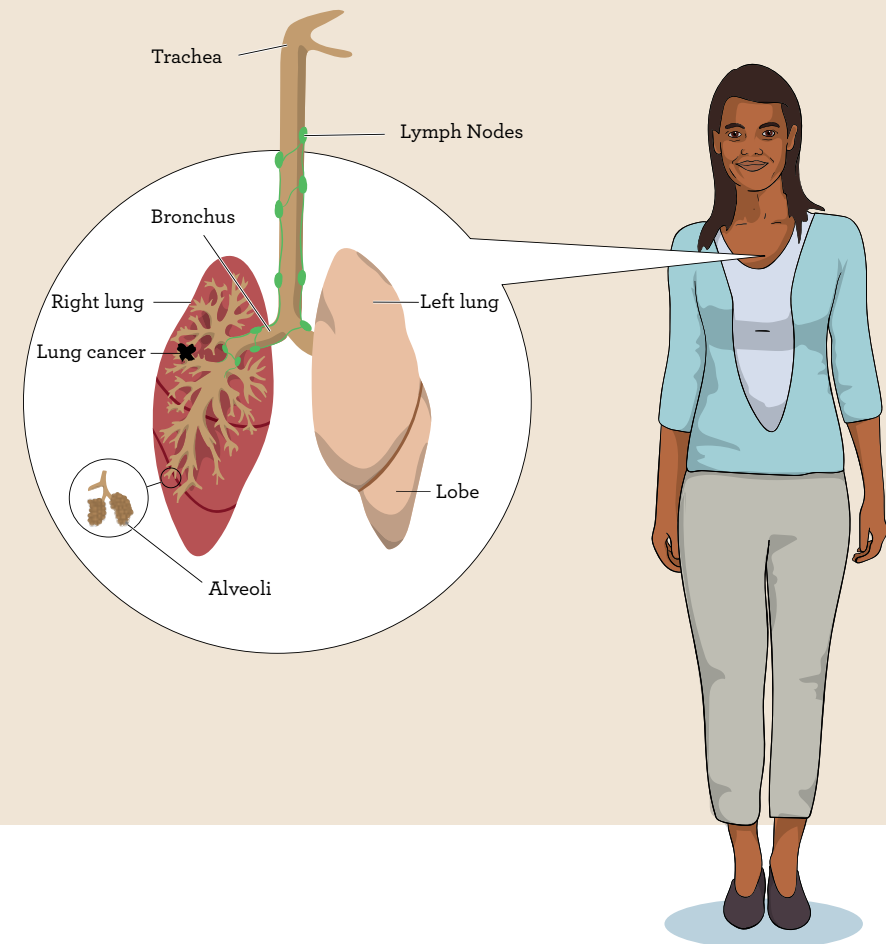
What is lung cancer?

The body is made up of many tiny cells. These cells grow and divide all the time. Lung cancer develops when cells in the lung grow differently to other cells. These different cells start growing out of control and join together forming lumps of tissue (tumours). As the cancer grows, it can stop the lungs from working well.

Lung cancer means that a tumour has started growing in the lungs. It can start anywhere in the lungs and can spread to other parts of the body. The picture below shows you the lungs.

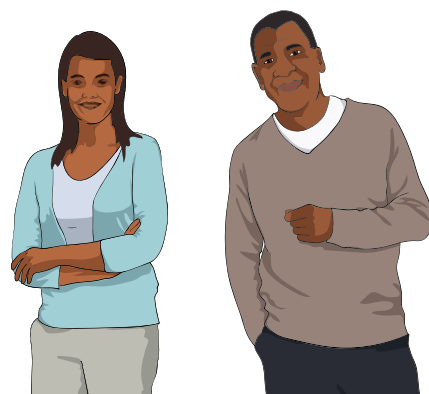
Your lungs are made up of:

- the windpipe (trachea)
- air tubes (bronchus)
- small groups of air sacs (alveoli)
- small lumps of tissue that help your body fight infections (lymph nodes)
- section of the lung (lobe).



Important things to know

- anyone can get lung cancer, even if you have never smoked but it is more common in people who have smoked
- lung cancer affects both men and women
- lung cancer occurs mostly in people aged 55 or over, although it can affect people of any age.



What tests might you have?

You will have some tests to work out what type of lung cancer you have and whether it has spread outside your lungs. The results of these tests will be given to you and explained by your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker.

The tests will help the doctor decide the best type of treatment to offer you. It can be helpful to take a support person with you. The table below explains the tests.

Test	Why it is important
<p>Taking your medical history and physical exam</p> <p>Your doctor will want to talk to you about how long you have been feeling sick or coughing or if you have had any pain. The doctor might take your height and weight, check your body and ask questions</p>	<p>This helps your doctor to understand what has been happening (your symptoms) and your general health. Knowing how strong your body is working will help the doctor to decide the right treatment for you.</p>
<p>Chest X-ray</p> <p>Takes a picture of the inside of your chest, showing your ribs, heart and lungs</p>	<p>This allows your doctor to see if there is anything unusual in your chest, like a tumour.</p>

<p>Chest computed tomography (CT) scan</p> <p>Produces a very clear picture of the inside of the lungs</p>	<p>This allows your doctor to find smaller tumours that could be missed by a chest X-ray.</p> <p>A chest CT scan can also show more detailed information about the tumour and any lymph nodes (glands) affected by the cancer.</p>
<p>Bronchoscopy</p> <p>A small camera is used to see inside your breathing tubes, usually through your nose or mouth</p>	<p>This allows your doctor to see the tumour and take a tissue sample (known as a biopsy) so it can be tested for cancer.</p>
<p>Needle Biopsy</p> <p>A test that sometimes uses a CT scan to guide a needle in taking a sample of lung tissue</p>	<p>This is another way your doctor can collect a tissue sample (a biopsy) to see if you have lung cancer.</p>
<p>Positron emission tomography (PET) scan</p> <p>A special kind of X-ray scan that will show any active cancer in your body. A special liquid will be injected into your body through a small needle for this test</p>	<p>This helps your doctor to see whether the lung cancer has spread to other parts of the body.</p>

What do the test results mean?

The test results provide important information about lung cancer and the stage of cancer, including:

- the type of tumour
- the size of the tumour
- the location of the tumour
- whether lung cancer has spread to other parts of the body
- the stage of the cancer.

The doctor puts all this information together (your medical history and test result information) to decide what stage the cancer is at. This is called ‘staging’ and it helps the doctor decide what is the best way to treat the cancer. There are four stages of lung cancer. There are different treatments for each stage and your doctor will talk to you about this.

Test results can be hard to work out. It is nice to have someone with you when the doctor is telling you about them. Ask your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker about anything you do not understand about your results.

It is good to have a support person or family member with you, as they can help by asking questions and talk with you about what was said. Writing things down can also help remind you what has been said and any questions you might have for the next time you see your doctor.

What happens next?

After you have been diagnosed with lung cancer, your doctor will talk to you about your treatment options.

Together, you and your family with the doctor can work out what is going to be the best treatment for you. You can also talk about where you can have treatment and when is the best time to start.



Your treatment team

You will see many health professionals once you are diagnosed with lung cancer. You can use these pages to keep a record of the health professionals you see and their contact details.



Health professional	Role in your care	
General Practitioner (GP)	Your local doctor who provides ongoing care. They will be able to help other doctors understand your medical history.	
	<table border="1"> <tr> <td>NAME:</td> <td>PHONE:</td> </tr> </table>	NAME:
NAME:	PHONE:	
Aboriginal and Torres Strait Islander Health Worker	Can offer support and information, and answer questions.	
	<table border="1"> <tr> <td>NAME:</td> <td>PHONE:</td> </tr> </table>	NAME:
NAME:	PHONE:	
Aboriginal Liaison Officer	Can offer support, and talk with other members of your treatment team.	
	<table border="1"> <tr> <td>NAME:</td> <td>PHONE:</td> </tr> </table>	NAME:
NAME:	PHONE:	
Oncology Nurse	Specialises in caring for people with cancer. They may care for you during and after your treatment, and may help to deliver some treatments.	
	<table border="1"> <tr> <td>NAME:</td> <td>PHONE:</td> </tr> </table>	NAME:
NAME:	PHONE:	

Health professional	Role in your care	
Respiratory Physician	Specialises in investigating and treating lung diseases, including lung cancer.	
	NAME:	PHONE:
Thoracic Surgeon	Specialises in performing lung cancer surgery.	
	NAME:	PHONE:
Radiation Oncologist	Specialises in radiotherapy (X-ray treatment).	
	NAME:	PHONE:
Medical Oncologist	Specialises in medicines to treat cancer (chemotherapy or targeted therapy).	
	NAME:	PHONE:
Palliative Care Physician	Specialises in helping patients by listening to what is important to them in managing pain and other symptoms.	
	NAME:	PHONE:

Some other health professionals you may meet

Physiotherapist, occupational therapist, exercise physiologist	Social worker	Radiologist
Psychologist, psychiatrist or counsellor	Community palliative care team	Pathologist
Pharmacist	Dietitian	Cancer care coordinator

Having lots of different health professionals look after you is called multidisciplinary care. This is the best type of care.

	NAME:	PHONE:
	NAME:	PHONE:

2 Types of treatment



There are lots of different ways to treat lung cancer. You might have one or more types of treatment. Your doctor will explain all this and what it means for you. You can have a say in what treatment you want to have.



Treatment for lung cancer depends on the type of cancer and where it is

Surgery	This treatment is used when the cancer has not spread and you are strong enough for an operation to remove the cancer.
Radiotherapy	This treatment is used to kill the cancer cells with X-ray beams.
Chemotherapy	This treatment is used to kill the cancer cells with medicines.
Targeted therapy	This treatment is used to target certain types of lung cancer.
Palliative care	This treatment can be used to relieve symptoms, and improve quality of life. It may also be used to reduce side effects of cancer treatment.

Lung cancer surgery

What is it?

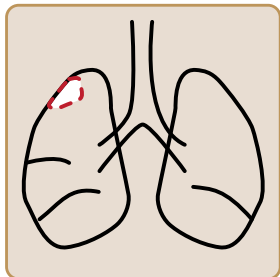


An operation that aims to remove the cancer or parts of the lung.

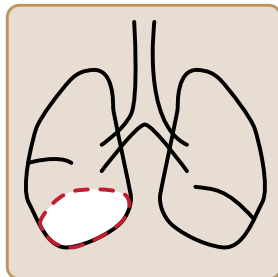
What might be done?

The surgeon will recommend the type of operation best for you. This could be:

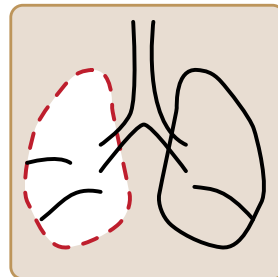
- a small part of the lung is removed (a wedge)
- a lobe of the lung is removed (a lobectomy)
- one whole lung is removed (a pneumonectomy).



Wedge resection
only a small part of the lung,
not the whole lobe is removed



Lobectomy
a lobe of the lung is removed



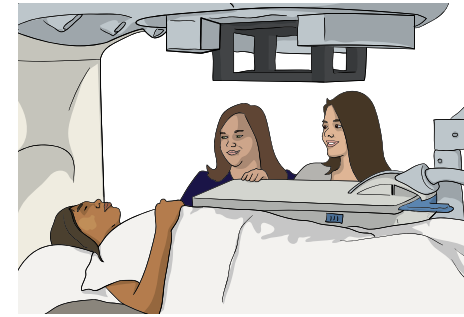
Pneumonectomy
one whole lung is removed

What is involved?

- lung surgery can take several hours
- you might be in hospital for several days
- the hospital might be far away from where you live and you may need to travel some distance to a hospital for lung surgery.

Radiotherapy

What is it?



A very special type of X-ray that aims to kill cancer cells in the area it targets.

When might you have it?

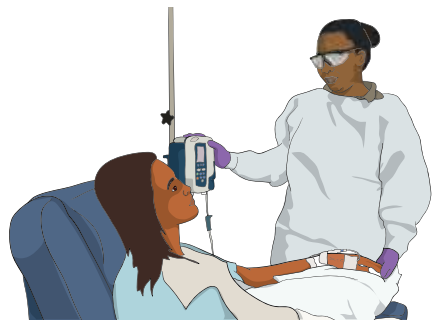
- after surgery
- instead of surgery or if surgery is not an option
- as a part of palliative treatment to relieve symptoms
- sometimes together with chemotherapy.

What is involved?

- the number of treatments will be different for each person
- treatment can range from a single treatment to 6 weeks of treatment
- you will need time to get changed and wait
- you lie on a bed while you have treatment
- each treatment will only take a few minutes
- radiotherapy won't hurt and you won't see or smell anything
- you may hear a buzzing sound from the machine
- depending on where you live, you may need to travel to a hospital for your treatment.

Chemotherapy

What is it?



A medicine that aims to kill cancer cells in and around the tumour and other parts of the body where it may have spread to.

When might you have it?

- before or after lung surgery
- with or without radiotherapy
- as a part of palliative treatment to relieve symptoms.

What is involved?

- the medicine may be put in your arm or hand through a tiny tube (like an IV drip) or taken as a tablet
- treatment will be given in 'cycles'. For example once a week for 3 weeks followed by a rest week. The length of a chemotherapy program will be different for everyone. It could be between 3 months to 6 months
- it will usually be given at a hospital in your town or nearest regional cancer centre, but sometimes tablets can be taken at home
- it is important to finish all cycles of your treatment.

Targeted therapies

What are they?



Medicines that are made to treat certain types of lung cancer cells.

When might you have them?

There are different types of cancer. If your lung cancer is a certain type these medicines will work on them in order to stop them growing or dividing.

What is involved?

Treatment will be different for each person and each type of lung cancer. The doctor will talk to you about your treatment. It is important to ask as many questions as you want, to understand what is best for you.

It may involve having some extra tests before or during treatment. Some of these treatments you can have at your home.

Traditional bush medicine



It is important to tell your treatment team if you are using, or thinking of using, any traditional bush medicines. Your doctor can talk to you about the best time and the best way to use your traditional bush medicines while you are having cancer treatment.

Don't forget, it is important to tell your treatment team what traditional medicines you may be using as some may work in a bad way with your cancer medication or stop it from working. Your treatment team can talk to you so that you can work out what will be best for you.

Questions to help you be prepared for your treatment

Asking questions is a good way to learn about your treatment.

Below are some example questions:

- Who is my number one person to go to?
- Who is in my treatment team?
- What do they all do?
- How long will my treatment take?
- How will the treatment affect my body?
- Will I need to travel for treatment?
- Who can come with me?
- Where can my family and I stay, and who can help me organise this?
- Is this the best treatment option for me?
- Are there any clinical trials available?

There is a lot to think about when you find out you have lung cancer. The doctor will talk to you about the treatments that you can have. It is important to know that it is OK to take the time to talk about treatment with your family and friends. They might ask you things you have not thought about yourself.

Write down your questions here and take them with you when you go back to your doctor and use them to help you decide what is best for you. When you are ready you can go ahead with treatment.

Write your own questions here:

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Looking after yourself during treatment



Treatment for lung cancer may cause changes to your body and make you feel unwell. These are known as side effects. If you are feeling bad, you should tell someone straight away. Talking about how you are feeling and doing healthy things can help you feel better.

Things you may or may not feel when having treatment for lung cancer

Below are some examples:

- feeling pain or soreness in areas where you have had treatment
- feeling short of breath
- coughing
- losing your hair
- feeling sick or vomiting
- losing weight
- feeling very tired (fatigued)
- having trouble going to the toilet (constipated)
- going to the toilet too often (diarrhea).



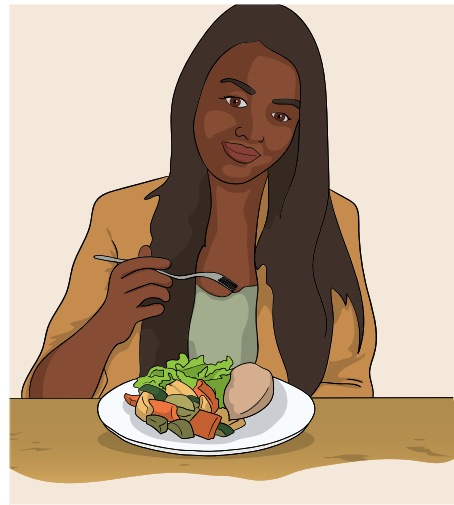
If you are in pain or if you have any of these side effects, tell your doctor, nurse, Aboriginal and Torres Strait Islander Health Worker or Aboriginal Liaison Officer straight away.

The doctor, nurse and dietitian will tell you the things to do before and during the treatment so you can manage the side effects better. The dietitian will tell you the amount and type of food to eat and to drink more fluids. There are also medicines and treatments you can have to help you feel better.

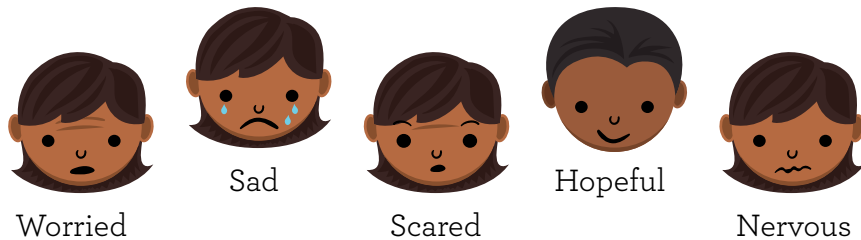
How to look after yourself during and after treatment

Below are some examples:

- get plenty of rest
- eat good food
- drink lots of water
- quit smoking
- cut down on grog (alcohol)
- do some gentle exercise like walking.



Treatment for lung cancer can make you feel



All these feelings are normal. It can help to speak with someone about how you are feeling.

Who can help you?



Family and friends



An Aboriginal and Torres Strait Islander Health Worker in your community, your doctor or nurse



A support group in hospital or in your community



Another person in your community who has had lung cancer or another type of cancer



Calling the Cancer Council Helpline on **13 11 20**. This is a free, confidential phone information and support service*

*If you need an interpreter, call the Translating and Interpreting Service (TIS) on **13 14 50**.

Questions about how you are feeling

Below are some example questions:

- Who can I talk to about how I am feeling?
- Is there a counsellor or psychologist you would recommend?

Write your own questions here:

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4

Going away for treatment



Depending on where you live, you may need to go to the city or a large regional centre for some or all of your treatment.

Before you leave home

Here is a list of things you might need to do before you leave home:

- find help to look after children or grandchildren
- get leave from work
- ask someone to mind your home and your pets
- check any bills that are due
- check what the weather will be like where you are going so you know what clothes to bring
- ask the Aboriginal and Torres Strait Islander Health Worker, Aboriginal Liaison Officer or Social Worker about what help you can get for you and your family to pay for things (financial support) or to find somewhere to stay (accommodation)
- find out who will meet you at the airport, hospital and hostel or accommodation.

Fill in the list with anything else you need to do here

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Who can help you?

	Calling the Cancer Council Helpline on 13 11 20 . This is a free, confidential phone information and support service*
	An Aboriginal Liaison Officer
	An Aboriginal and Torres Strait Islander Health Worker in your community, your doctor or nurse
	A Social Worker
	Hospital administration

*If you need an interpreter, call the Translating and Interpreting Service (TIS) on **13 14 50**.

Help with travel

There are patient support schemes that may be able to help you pay for your travel and somewhere to stay during treatment. Support schemes are different in each State and Territory. Talk to your local Aboriginal and Torres Strait Islander Health Worker, Aboriginal Liaison Officer, doctor or nurse for more information.

Personal support for you

You can bring a support person with you. Your support person may be a family member or a friend. Some hospitals have rules about how many support people can be with you during treatment. Talk to your Aboriginal and Torres Strait Islander Health Worker, Aboriginal Liaison Officer or nurse about how many support people can come with you.

What to bring with you to hospital:

- referral letter from your doctor
- travel and accommodation paperwork
- Medicare card, private health insurance card and any pension or concession cards
- regular medicine you may be taking (including any bush medicine)
- identification (such as driver's licence)
- mobile phone and charger
- comfortable clothes
- money or bank card.

It is a good idea to label your belongings so they don't get lost.

Questions about going away

Asking questions can help you find out about going away for treatment and staying in hospital.

Below are some example questions:

- Will I need to travel for treatment?
- How long will I be away from home for?
- If I take time off work, how do I apply for temporary income support?
- Who do I talk to about my travel and accommodation?
- Can I get help with travel and accommodation costs?
- How can I find out about home help while I am going through treatment?

Write your own questions here:

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Hospital rules

Different hospitals will have different rules. Check with your hospital about:



Times when you can use your mobile phone



Times when your friends and family can visit



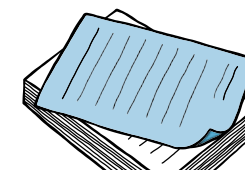
The number of family and friends who can visit at one time

When you leave hospital, you might feel



If you feel worried or nervous about finishing treatment, speak to your doctor, nurse, Aboriginal and Torres Strait Islander Health Worker or Aboriginal Liaison Officer.

What you might bring home



Discharge information

Give this information to your local doctor when you get home.



New medicine

Ask your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker if you're confused about your medicine.

You might like some help when you get home

Your doctor, nurse, Aboriginal and Torres Strait Islander Health Worker or Aboriginal Liaison Officer can arrange for someone to visit you at home, and make sure you're OK.

5

Palliative care



Palliative care improves quality of life for people with cancer. It's not just for people who are about to die, although end-of-life care is a part of palliative care. This section will help you understand what palliative care is and why it is important.

What is palliative care?

Palliative care can provide pain relief and manage other symptoms. Palliative care is important throughout treatment and end-of-life care. Having palliative care can make sure you and your family get the services that you need not just for your treatment. It helps with your needs at home, how you are feeling, your spirit and what is important to you, like going home or having your friends and family with you. It can also help with any practical needs you may have.

Palliative care brings together many different services and people, which include:

- your doctor
- Palliative Care Physician or nurse
- Aboriginal Liaison Officer
- Aboriginal and Torres Strait Islander Health Worker
- Home and Community Care Worker
- spiritual guide or religious advisor
- family, friends and community.



How can palliative care help?

It can provide comfort and support by:

- helping make you comfortable for as long as possible
- managing problems such as pain
- being there for you, so you are not alone.

When do I have it?

You can have palliative care at any time during your treatment. Talk to your doctor, nurse, Aboriginal and Torres Strait Islander Health Worker or Aboriginal Liaison Officer early on about palliative care.

Who organises palliative care?

Usually your doctor, nurse, Aboriginal and Torres Strait Islander Health Worker or Aboriginal Liaison Officer can help with this.

Do I have to pay for it?

Palliative care services are mostly free. You may have to pay for some things like the hire of special equipment, medicines, dressings or treatment but your doctor or Aboriginal and Torres Strait Islander Health Worker or palliative care nurse can tell you about this.

Where do I have palliative care?

You may have it at home, in hospital or at a hospice (palliative care unit). A hospice is a place more like a home than a hospital where you can be cared for by trained staff if you don't feel you can manage at home.

You can move between these places if your needs change. You can stay for a short or long time.

Usually, you and your family can choose where to have palliative care. It may depend on what is available where you live.

If you are at home, special services may be put in place to help you and your family, like nursing care and equipment hire.



6

Getting affairs in order



When you've been diagnosed with lung cancer, it can be useful to get your affairs in order. This includes organising personal, financial and legal affairs, collecting all important paperwork and notifying your family about your wishes should there be any complications with your lung cancer. It can be useful to have your support person help with this.

Why this is important

While this can be a hard time to think about this, it is important to have this information in place so you can focus on treatment and living. Having to think about these things during treatment when you're trying to get better could make you feel stressed or more tired than you need to be.

You can talk to your doctor, Aboriginal and Torres Strait Islander Health Worker, Aboriginal Liaison Officer or nurse about who to talk to about your specific legal and financial situation. You can ask your support person to help.

Organising paperwork

It is a good idea for you to have all of your paperwork in one place. This will make it easier if, for example, you need to be in hospital for a long time and your support person has to help with financial and legal matters. Important documents to get together might include:

- birth, marriage and divorce certificates
- bank and credit card information
- investment details
- Centrelink and Medicare details

- superannuation and insurance information (you may be able to access your superannuation early depending on your condition).
- house title/rental lease documents
- a Will
- passport
- advance care plan
- funeral plan.

Sharing your wishes

It is important to speak about your wishes to your family regarding legal, medical and end-of-life decisions they might have to make. You can tell someone close to you where you keep your legal documents or how to contact your lawyer if needed.

Who can help you and your family?

	An Aboriginal Liaison Officer
	An Aboriginal and Torres Strait Islander Health Worker in your community, your doctor or nurse
	A Social Worker
	Calling the Cancer Council Legal Referral Service on 13 11 20 can help you find out more about your superannuation or insurance information*†
	Visit the Advance Care Planning Australia website at www.advancecareplanning.org.au

*If you need an interpreter, call the Translating and Interpreting Service (TIS) on **13 14 50**. †Not available in all states and territories.

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Information for families and friends



You may be reading this booklet because you are a family member or friend supporting your loved one with lung cancer. Being a support person or carer can be difficult. You may find it hard knowing what to say or how best to help.

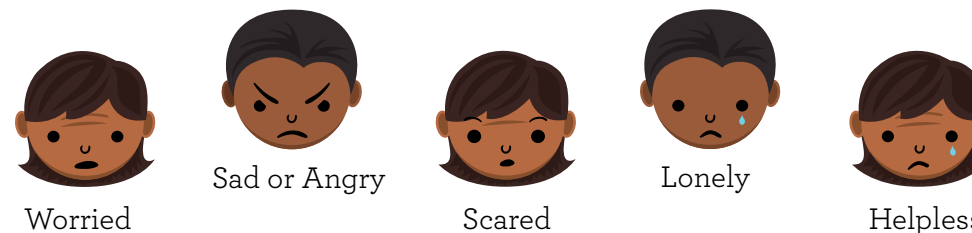
How you can help

As a support person, you play an important role in your loved one's lung cancer treatment by giving them loving care, looking after their spirit, helping them manage their finances (if needed) and talking to extended family and friends.

It is important to ask your loved one what support they would like. If they agree, you could attend appointments with them and you can both start to understand what is going to happen. There is a lot of information to think about and it can help them having you there to ask questions and remember what is being said.





You can talk to the doctor, nurse or Aboriginal and Torres Strait Islander Health Worker about support services or how to get in touch with someone else who has had cancer and knows what to expect.

How you might be feeling



All these feelings are normal. It can help to speak with someone about how you are feeling.

Who can help you and your loved one?

	Family, friends or people in your community
	An Aboriginal and Torres Strait Islander Health Worker in your community, your doctor or nurse
	Another person in your community who has had lung cancer or another type of cancer
	Calling the Cancer Council Helpline on 13 11 20 . This is a free, confidential phone information and support service*

*If you need an interpreter, call the Translating and Interpreting Service (TIS) on **13 14 50**.

Taking care of yourself

It is also important that you take care of your own health and wellbeing. You can do this by:

- talking about any concerns or fears you have with an Aboriginal and Torres Strait Islander Health Worker, a nurse or a doctor
- talking about how you are feeling with your own family and friends who are giving you support
- keeping up with seeing family and friends
- eating healthy food to keep up your energy
- exercising regularly
- getting enough sleep to make sure you feel rested.



Discussing your loved one's wishes

This can be a difficult conversation to have but it is an important one. Knowing your loved one's wishes early, when they are diagnosed with lung cancer, can give you both a sense of relief that if anything were to happen you would know their wishes and what to do.

You can get advice from an Aboriginal and Torres Strait Islander Health Worker, an Elder or respected member of your community, a counsellor, social worker or church worker to help you with the discussion with your loved one.

As a support person it is important that you speak with your loved one's treatment team to make sure they know your loved one's wishes so that they can work with you if needed. It is important to remember that the doctor, nurse and Aboriginal and Torres Strait Islander Health Worker want the best for your loved one too. It is good to ask them about what cultural practices can happen at the hospital so they can assist if anything were to happen.

Important topics to discuss with your loved one

Some things to discuss are:

- who should be contacted if their health gets worse
- if the cancer is too advanced would they like to spend their time at home
- if they are too sick to go home
 - who should know and who would they want to have around them
 - what cultural practices should happen, for example:
 - inviting a respected Elder
 - smoking ceremony
 - inviting a priest, chaplain or spiritual guide



What does that word mean?



Throughout your cancer treatment, you will hear lots of medical words. Remember that it is OK to ask your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker to explain something that you do not understand. Here are some common words to do with lung cancer.

Word	Meaning
Advanced cancer	Cancer that has spread into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.
Alternative therapies	Treatments used instead of usual treatments.
Alveoli	The tiny air sacs in the lungs, where oxygen enters the blood and carbon dioxide leaves it.
Anaesthetic	A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a person to lose consciousness or go into a deep sleep for a period of time.
Complementary therapies	Treatments or therapies that can be used alongside usual therapies.
CT scan	A computerised tomography scan. This type of scan uses X-rays to provide a very clear picture of the inside of the body.
Intravenous (IV)	A tube inserted into a vein.
Lobe	Section of an organ. For example, the left lung has two lobes and the right lung has three lobes.

Word	Meaning
Lungs	The two spongy organs in the chest cavity, made up of large numbers of tiny air sacs. The lungs are used for breathing.
Lymph nodes	Small, bean-shaped structures that act like filters, removing germs that can hurt you.
Metastasis	A cancer that has spread from another part of the body. Also known as secondary cancer.
MRI scan	A magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body. It does not hurt but can be noisy.
Multidisciplinary care	A group of people get together to form a team and decide on the best approach to cancer treatment and planning for each person.
Non-small cell lung cancer	One of the two main groups of lung cancers. Includes squamous cell carcinoma, adenocarcinoma and large cell carcinoma.
Oesophagitis	Temporary difficulty and pain in swallowing as a result of a long course of radiotherapy (i.e. several weeks).
Oesophagus	The tube that carries food from the throat into the stomach.
Oncologist	A doctor who specialises in the study and treatment of cancer.
Palliative care	The holistic (complete) care of people with life-limiting illness, their families and carers. It aims to improve quality of life by looking at all your needs such as physical, emotional, spiritual, social and practical. It is not just for people who are about to die, although end-of-life care is a part of palliative care.
Pathology	Tests that involve examining blood, tissue or cells from the body.
PET scan	A positron emission tomography scan. A special kind of X-ray scan that uses a radioactive liquid to identify cancer cells in the body.

Word	Meaning
Pharmaceutical Benefits Scheme (PBS)	A scheme managed by the government that provides medicines at a subsidised price to Australian residents who hold a current Medicare card and to overseas visitors from countries with which Australia has a Reciprocal Health Care Agreement.
Prognosis	What is likely to happen because of a person's disease.
Respiratory system	The system of the body responsible for breathing.
Risk factors	Things that increase your chance of getting lung cancer.
Small cell lung cancer	A type of cancer strongly linked with cigarette smoking.
Sputum	Liquid coughed up from the lungs. Also known as phlegm.
Staging	Performing tests to determine how far cancer has spread. Stage 1 Early stage disease where cancer is in one lung or section of the lung (lobe). Stage 2 Cancer may be in the lung, some lymph nodes, or the chest wall. Stage 3 Cancer has spread to lymph nodes in the chest or in more than one lobe. Stage 4 Cancer has spread beyond the lung where it started and is in other parts of the body.
Steroids	Drugs used to relieve swelling and inflammation.
Symptoms	What a person feels, notices or experiences.
Targeted therapies	Drugs that stop the growth of particular types of cancer cells. Also known as biological therapies.
Tissue	A collection of cells that make up a part of the body.
Trachea	The windpipe. This is the airway that brings air inhaled from the nose and mouth into the lungs.
Tumour	A growth that is made up of damaged cells that have clumped together. They grow in an unusual way on or in the body.

Helpful contacts

Cancer Australia

canceraustralia.gov.au

Cancer Australia is the Government's national cancer control agency. The Cancer Australia website provides evidence-based information about a range of cancers, including lung cancer.

Cancer Council Australia

Helpline: 13 11 20

cancer.org.au

This website has links to the State and Territory Cancer Councils, which have information about cancer resources available in each State and Territory.

Lung Foundation Australia

Free call: 1800 654 301

lungfoundation.com.au

This website provides information on lung disease, its treatment and patient support.

Carers Australia

Free call: 1800 242 636

carersaustralia.com.au

This website has links to the State and Territory Carers Associations, which have information about cancer resources available in each State and Territory.

Palliative Care Australia

Call: 02 6232 0700

palliativecare.org.au

This website has helpful information for patients, carers and health professional on palliative care and services available.

The illustrations for this booklet were created by Jordan Lovegrove, a Ngarrindjeri man from South Australia who works for Dreamtime Creative. They were created electronically, with Jordan scanning photographic images and using them as a base to trace outlines in illustrator. This created a stylised illustrative feel, with a uniform look to the images. It presented an appropriate and practical approach to representing Aboriginal and Torres Strait Islander people along the cancer care continuum.

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The artwork 'Our Journeys' represents the experience of Aboriginal and Torres Strait Islander people with cancer. The white dots are the journey of each individual; the patterned areas are the different landscapes and regions of Australia; and the colours are the different cancer types. Cancer Australia, as the leading agency shaping cancer control in Australia, is depicted by the central ochre meeting place which draws stakeholders together to share ways to improve cancer outcomes. The kangaroo prints and the fish leading to and from the meeting place represent the flow of information and engagement between Cancer Australia and Aboriginal and Torres Strait Islander people.

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Artist: Jordan Lovegrove, Ngarrindjeri, Dreamtime Public Relations, www.dreamtimepr.com