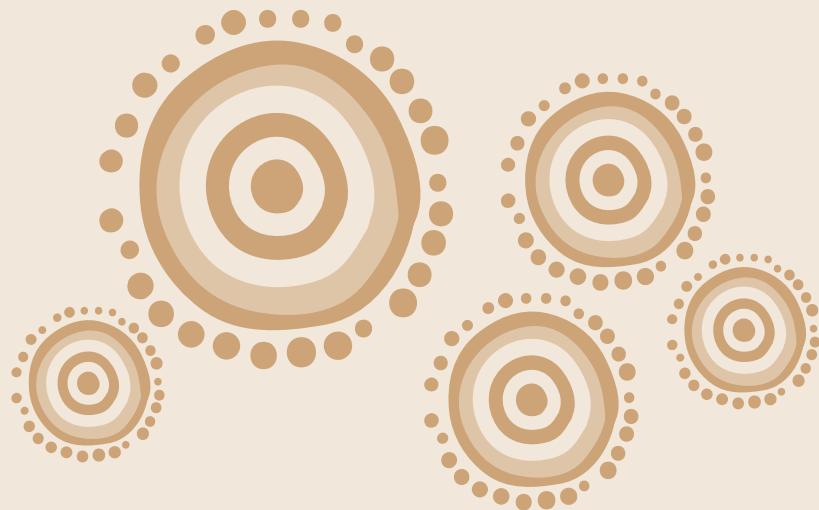




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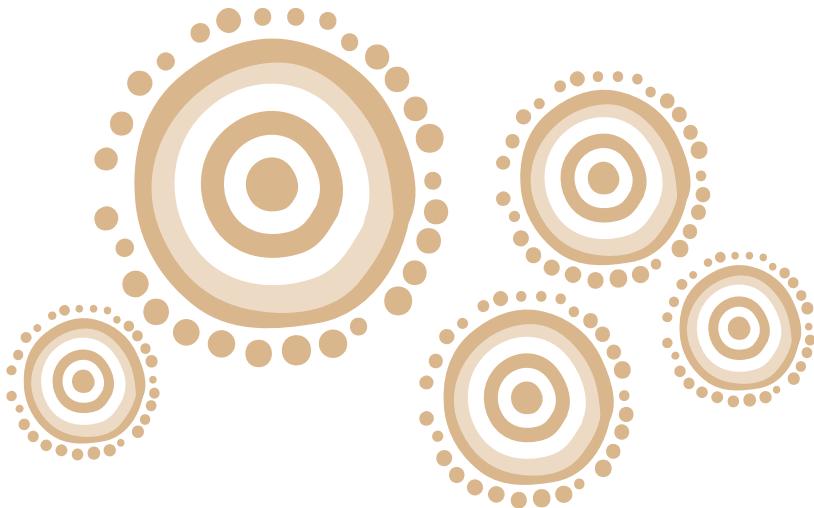


A handbook for Aboriginal and
Torres Strait Islander Health Workers



Cancer Australia

LUNG CANCER IN OUR MOB



**A handbook for Aboriginal and
Torres Strait Islander Health Workers**



**Helping Health Workers provide information
and support to Aboriginal and Torres Strait
Islander people with lung cancer**

Lung cancer in our mob: a handbook for Aboriginal and Torres Strait Islander Health Workers resource was prepared and produced by:

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- Donna Moroney, Senior Project Officer
- Lauren Kinsella, Senior Project Officer
- Jeanette Nolan, Production Coordinator

Acknowledgement of country and cultural diversity



Cancer Australia acknowledges the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present.

Cancer Australia recognises that ‘Aboriginal and Torres Strait Islander people’ is the preferred term for referring to Aboriginal peoples and Torres Strait Islanders collectively. This term recognises the distinct cultures, languages and homelands of Australia’s Indigenous communities.

In this document ‘Indigenous Australians’ may be used in place of ‘Aboriginal and Torres Strait Islander people’ when presenting information in tables or graphs or comparing cancer statistics with other groups such as non-Indigenous Australians so that the key information provided in the document is clearly presented.

In this document ‘Indigenous Australians’ refers to Aboriginal and Torres Strait Islander peoples from Australia, and does not include Indigenous people from other countries.

Information from the 2011 Census suggests that 3% of the Australian population identified as being of Aboriginal and/or Torres Strait Islander origin.

About this handbook



Lung Cancer in our mob: a handbook for Aboriginal and Torres Strait Islander Health Workers (the Handbook) has been written to help health professionals support Aboriginal and Torres Strait Islander people with lung cancer. Increasing the understanding of lung cancer may help to encourage earlier investigation of symptoms, and contribute to the quality of life of people living with lung cancer.

Who should use this handbook?

This handbook has been written for **Aboriginal and Torres Strait Islander Health Workers, Health Practitioners and Aboriginal Liaison Officers** involved in the care of Aboriginal and Torres Strait Islander people with lung cancer in community and clinical settings.

The handbook may also be used as a reference tool by:

- nurses and other allied health professionals working with Aboriginal and Torres Strait Islander people
- students undertaking the general cancer unit as part of the Aboriginal and Torres Strait Islander Health Worker qualification.

Throughout this handbook, we use the term Aboriginal and Torres Strait Islander Health Workers to refer to Health Workers, Health Practitioners and Aboriginal Liaison Officers.

Chapter 1

Lung cancer: getting the facts straight

Chapter 1. Lung cancer: getting the facts straight



This chapter provides some facts about lung cancer and the role of the Aboriginal and Torres Strait Islander Health Worker in supporting people with lung cancer, their families and communities.

1.1 What is cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. Cancer occurs when abnormal cells grow and multiply in an uncontrolled way. These abnormal cells can damage or invade the surrounding tissues, or spread to other parts of the body, causing further damage.

Most cancers start in a particular part of the body or organ; this is called the primary site or primary tumour. Tumours can be benign (not cancer) or malignant (cancer).

Benign tumours (not cancer)

Benign tumours do not spread outside their normal boundary to other parts of the body. Some benign tumours are precancerous and may progress to cancer if left untreated. Other benign tumours do not develop into cancer. However, if a benign tumour continues to grow at the original site, it can cause a problem by pressing on nearby organs.

Malignant tumours (cancer)

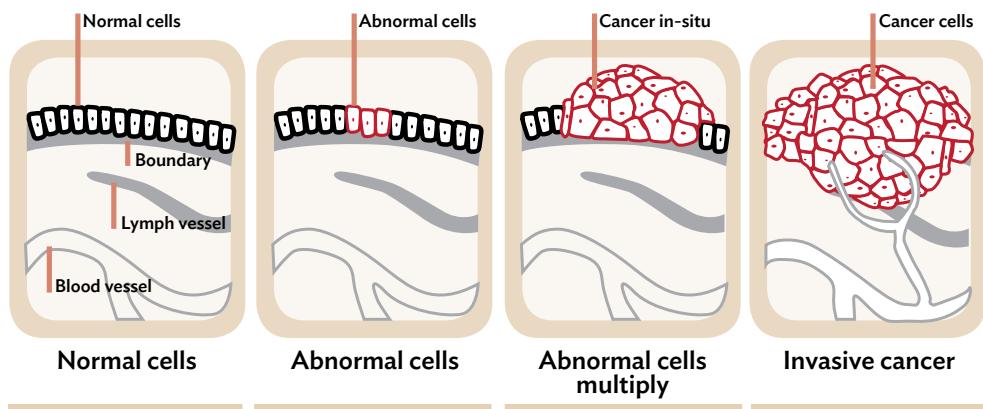
A malignant tumour is made up of cancer cells. When it first develops, this malignant tumour may be confined to its original site. This is known as a cancer *in situ* (or carcinoma *in situ*). If these cells are not treated, they may spread beyond their normal boundaries and into surrounding tissues, becoming invasive cancer.

How cancer spreads

Sometimes cancer cells break off the primary tumour, enter the bloodstream or lymphatic system, and travel to a new organ to form secondary tumours. This is called metastasis.

The term ‘cancer’ refers to more than 100 different diseases. Most cancers are named by the organ or type of cell in which they are formed. For example, cancer that begins in the lung is called lung cancer. Figure 1.1 illustrates how a cancer is formed.

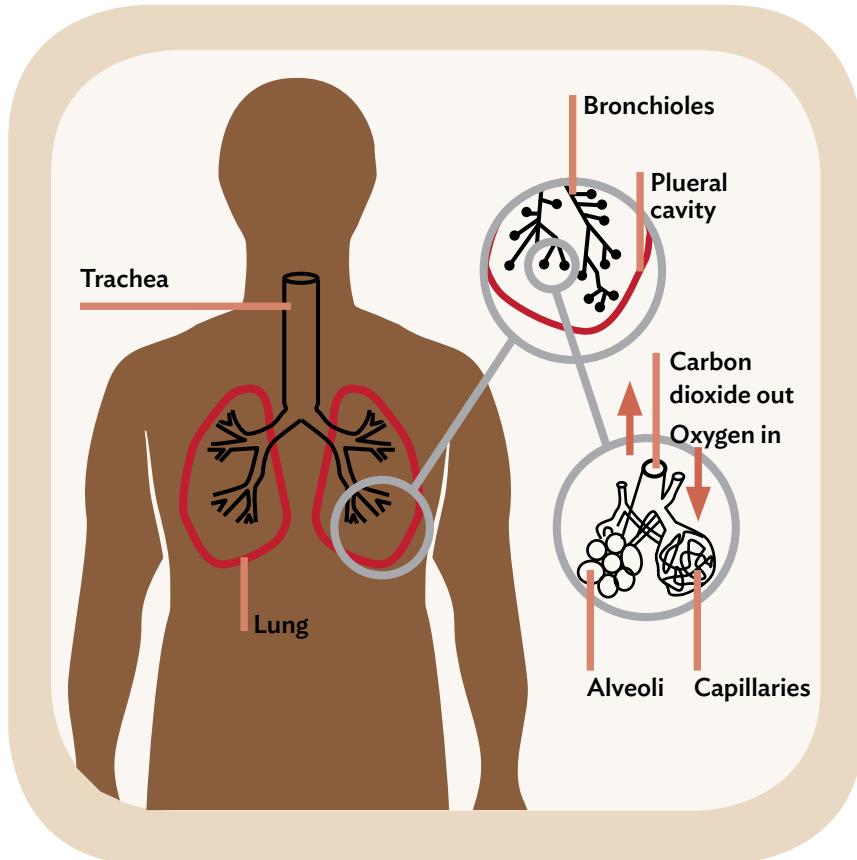
Figure 1.1 How cancer starts.



1.2 What is lung cancer?

Lung cancer is the name given to a cancer that starts in the lungs.^{1,2} Lung cancer can start anywhere in the lungs, including the trachea, bronchi, bronchioles and alveoli (Figure 1.2).^{1,2} As the cancer grows, it can stop the lungs from working well. If left untreated, lung cancer can spread to other parts of the body. This process is known as metastasis.^{1,2}

Figure 1.2 The respiratory system



Fast fact

There is no word meaning 'cancer' in most, if not all Aboriginal and Torres Strait Islander languages. Unlike many other illnesses, the concept of cancer is not embedded in traditional Aboriginal and Torres Strait Islander story-telling.

What are the different types of lung cancer?

Lung cancer can start in different cells in the lung. There are two main types of lung cancer, named because of how the cancer cells appear under a microscope. These are small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC).^{1,2} Table 1.1 gives more detail about these types of lung cancer.²

Table 1.1 Overview of the two main types of lung cancer

Small cell lung cancer (SCLC)	Non-small cell lung cancer (NSCLC)
Makes up about 12% of lung cancers*	Makes up approximately 62% of lung cancers*
(Usually starts in epithelial cells that line the surface of the main bronchi)	(Mainly affects cells lining the bronchi and smaller airways)
Most aggressive type of lung cancer	Tends to grow and spread more slowly than SCLC
Tends to spread widely through the body, early in the course of the disease	Includes a variety of invasive tumours, including squamous cell carcinoma, adenocarcinoma and large cell carcinoma

*Other specified carcinoma and other unspecified malignant neoplasm comprised the additional 25% of all lung cancer types²



Fast fact

Cancer that first develops in other parts of the body can spread to the lungs. This is called a secondary cancer, and is not classified as lung cancer. This is because cancers are named according to where they first develop in the body.³

1.3 Facts about lung cancer

- In the last 10 years, the most common cause of cancer death in Aboriginal and Torres Strait Islander people was lung cancer, followed by liver cancer, breast cancer (in women), cancer of unknown primary site and bowel cancer.
- Overall, Aboriginal and Torres Strait Islander Australians are 70% more likely to die from lung cancer than non-Indigenous Australians.[†]
- Choosing to quit smoking can reduce the risk of getting many cancers, including lung cancer.
- The earlier lung cancer is found, the better survival is likely to be.

Sometimes it can be hard for your patients to separate the facts from the fiction. Table 1.3 will help you to talk to your patients about common misconceptions about lung cancer.

Table 1.3 Common misconceptions about lung cancer

Fiction	Fact
“I’m young, I won’t get lung cancer”	Although lung cancer occurs mostly in people over 55, it can affect people of any age.
“I never smoked, I won’t get lung cancer”	Anyone can get lung cancer, even if you have never smoked.
“If I have lung cancer, nothing can be done about it anyway”	New treatments are likely to continue to improve outcomes for people affected by lung cancer.
“I’ve had this cough for weeks, it will clear up eventually”	A new cough that lasts for 3 weeks or more, or a changed cough, could be symptoms of lung cancer. A GP, nurse or Health Worker should be seen as soon as possible.
“I need to be strong and face lung cancer alone”	It is important for people with lung cancer to be open and honest with family and health professionals so that they can access the help and support they need.

[†] Australian Institute of Health and Welfare 2014. *Cancer in Australia: an overview 2014*. Cancer series No. 90. Cat. no. CAN 88. Canberra: AIHW.

1.4 The role of the Aboriginal and Torres Strait Islander Health Worker

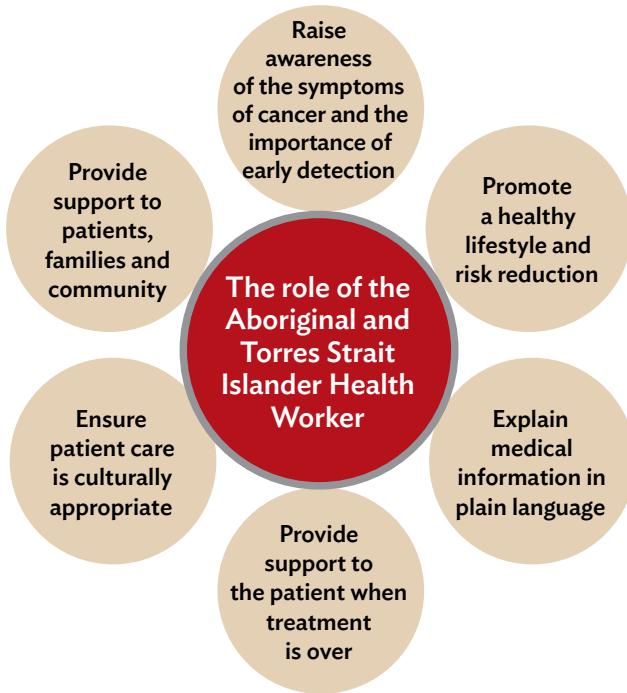
Aboriginal and Torres Strait Islander Health Workers play a vital role in delivering safe, high-quality and supportive care to patients in community and clinical settings.

In practice, the role of the Aboriginal and Torres Strait Islander Health Worker may vary depending on location, the needs of the patient and their health care team and the health service in which they work.

In this handbook, we talk about different points of the lung cancer pathway, including diagnosis, treatment, supportive care and end-of-life care. An Aboriginal and Torres Strait Islander Health Worker provides information, referral, support and guidance for Aboriginal and Torres Strait Islander people with lung cancer, and their families and communities at all of these points (see Figure 1.4).



Figure 1.4 The role of the Aboriginal and Torres Strait Islander Health Worker in supporting people with cancer



Raising awareness of the symptoms of lung cancer and the importance of early detection

For many cancers, including lung cancer, treatment outcomes and survival can be improved by diagnosing and treating the disease early.³ However, diagnosis and treatment of lung cancer can be delayed by a number of factors:

- some people may not recognise the symptoms of lung cancer, as these can be vague and mimic symptoms of many other conditions
- some people may not be aware that lung cancer can occur in non-smokers or young people
- some people may be ashamed or embarrassed to visit their doctor due to the stigma associated with lung cancer
- some people may believe that there are no effective treatments available for lung cancer, so there is no point visiting the doctor.³

Raising awareness about lung cancer is an important part of the role of an Aboriginal and Torres Strait Islander Health Worker. Table 1.4 has some key messages that you may like to share with your communities.

Table 1.4 Key messages about lung cancer

Key message	Details
People who don't smoke can get lung cancer	Although smoking is a common risk factor for lung cancer, it is important to highlight that this condition can affect non-smokers and young people, as well as those who smoke ³
The symptoms of lung cancer can be non-specific⁵	A key message to share with your community is that, if a person experiences any of these five key symptoms, they should visit their GP promptly, irrespective of their age and whether or not they smoke: <ul style="list-style-type: none">• persistent cough (lasting longer than 3 weeks)• change in cough• coughing up blood• a chest infection that won't go away• shortness of breath
No-one deserves to get cancer	There is a lot of stigma associated with lung cancer, largely because of its association with smoking. Some people may not seek medical assistance for symptoms because they are ashamed or embarrassed about the association with their smoking As a result, it is vital to increase community awareness that no-one deserves to get cancer, regardless of whether or not they are a smoker ³
Cancer is not a death sentence	It is commonly believed in many Aboriginal and Torres Strait Islander communities that a diagnosis of cancer is a death sentence, and that cancer is not treatable. To ensure the early diagnosis and treatment of lung cancer, there is a need to promote awareness around the fact that effective treatments are available, and that these are improving all the time. ² In particular, people who have surgery in the early stages of the disease have the best chance of cure. However, surgery may no longer be an option as the cancer progresses ¹

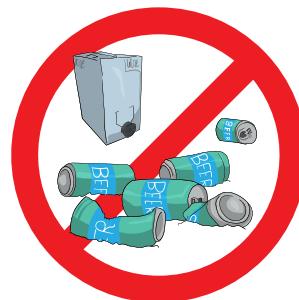
Promoting a healthy lifestyle

Current evidence suggests that about one-third of cancer deaths in Australia are due to known and avoidable risk factors.

An important part of the role of an Aboriginal and Torres Strait Islander Health Worker is to promote a healthy lifestyle that reduces the risk of developing diseases such as lung cancer.

Aboriginal and Torres Strait Islander Health Workers can promote healthy behaviours and strategies to encourage people to stop smoking, as well as broader cancer prevention and early detection strategies, including:³

- promotion of healthy lifestyles (stopping smoking, healthy diet, healthy weight, limiting alcohol intake)
- reducing risky behaviours (stopping smoking, ‘sun smart’ behaviours).



Explaining medical information in plain language

Patients will hear a lot of complex medical language during their investigation, diagnosis and treatment for lung cancer.

Aboriginal and Torres Strait Islander Health Workers can help patients to understand what tests and treatment they are having, and why these are important, by explaining things in plain language.

It might also be useful to explain some practical aspects of treatment for lung cancer, including what will happen when a patient goes to hospital, what they may need to bring and how long treatment will take.

This will help the patient, their family and the community better understand lung cancer.

Ensuring patient care is culturally appropriate

Patients will move through a variety of health care settings and meet different health professionals and service providers while their symptoms are being investigated and during their treatment for lung cancer.

Aboriginal and Torres Strait Islander Health Workers can provide guidance to the health professionals involved in lung cancer treatment and care about cultural issues that might be important to Aboriginal and Torres Strait Islander patients, their families and carers. This will help to ensure that care is provided in an appropriate manner.

Providing support to the patient, their family and community

Communicating clearly and developing trust with patients and their families and carers is vital.

Yarning is a good way to share knowledge and information about cancer.

Aboriginal and Torres Strait Islander Health Workers can talk with patients and their families about how they are feeling, and address any questions and concerns they might have. This support is important during diagnosis and treatment for lung cancer. People who have finished treatment for lung cancer are also likely to need support – this is often called ‘survivorship care’ (see Chapter 8).

Aboriginal and Torres Strait Islander Health Workers can also provide information to patients and their family, carers and community about support services and peer support programs and how they can be accessed.

LUNG CANCER: GETTING THE FACTS STRAIGHT

Chapter 2

Lung cancer in Aboriginal and Torres Strait Islander people

2

Chapter 2: Lung cancer in Aboriginal and Torres Strait Islander people



This chapter provides information on incidence, mortality and survival for Aboriginal and Torres Strait Islander people with lung cancer.

2.1 Incidence of lung cancer

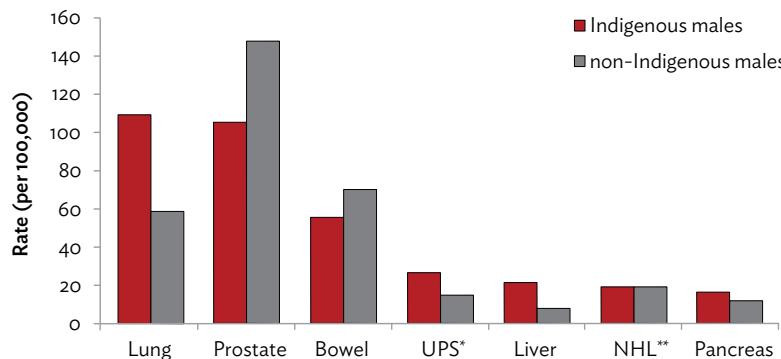
Some facts about lung cancer incidence in Aboriginal and Torres Strait Islander people:

- lung cancer is the most commonly diagnosed cancer[†]
- lung cancer accounts for 1 in 6 of all cancers diagnosed[†]
- Aboriginal and Torres Strait Islander people are 70% more likely to be diagnosed with lung cancer, compared with non-Indigenous Australians. This may be explained by higher rates of smoking[†]
- lung cancer incidence is higher among Aboriginal and Torres Strait Islander men, compared with women^{*4}
- lung cancer incidence is higher for Aboriginal and Torres Strait Islander people living in more remote areas^{*4}.

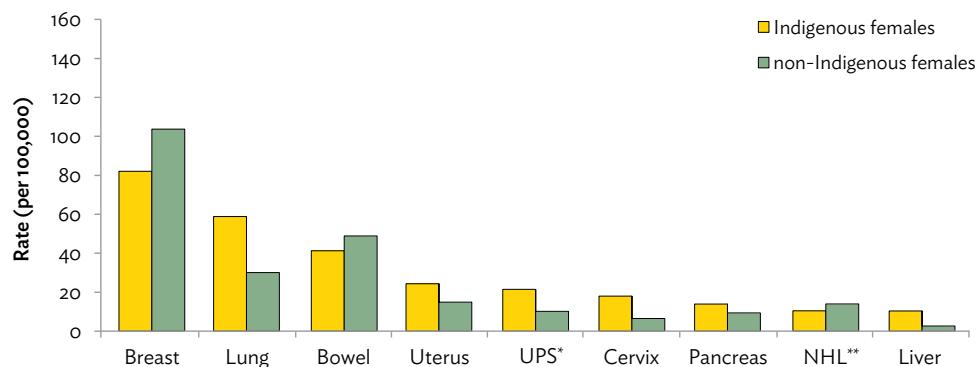
**Figures represent Aboriginal and Torres Strait Islander people living in NSW, Queensland, Western Australia and the Northern Territory between 2004 and 2008. Complete national data are not currently available.*

† Australian Institute of Health and Welfare 2014. Cancer in Australia: an overview 2014. Cancer series No. 90. Cat. no. 88. Canberra: AIHW.

What were the most commonly diagnosed cancers in Aboriginal and Torres Strait Islander males in 2004-2008 (in NSW, Qld, WA and NT)⁶?



What were the most commonly diagnosed cancers in Aboriginal and Torres Strait Islander females in 2004-2008 (in NSW, Qld, WA and NT)⁶?



*UPS stands for Unknown primary site. **NHL stands for Non-Hodgkin lymphoma.

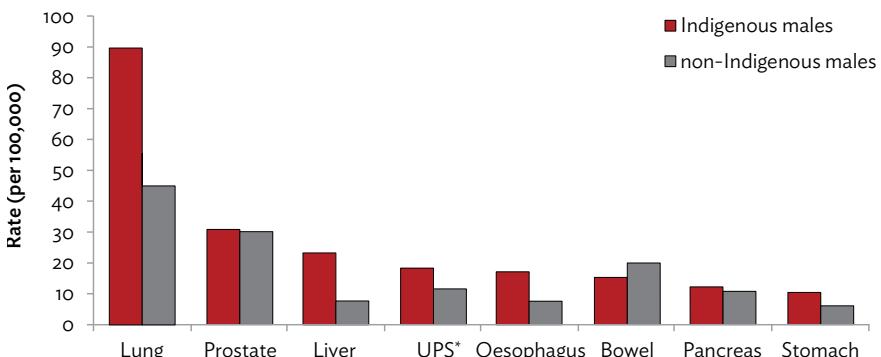
2.2 Mortality from lung cancer

Some facts about lung cancer mortality in Aboriginal and Torres Strait Islander people:

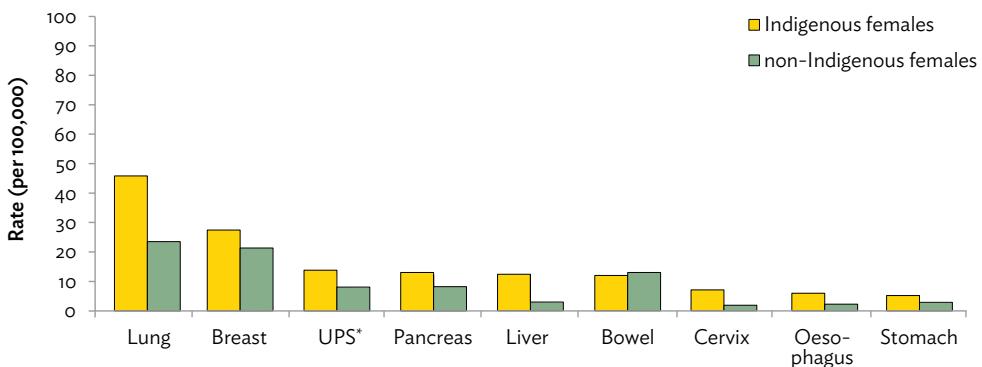
- lung cancer is the leading cause of cancer death[†]
- lung cancer accounts for about 1 in 4 of all cancer deaths[†]
- Aboriginal and Torres Strait Islander people are 70% more likely to die from lung cancer, compared with non-Indigenous Australians[†]
- Aboriginal and Torres Strait Islander men are twice as likely to die from lung cancer, compared with Aboriginal and Torres Strait Islander women^{*4}.

**Figures represent Aboriginal and Torres Strait Islander people living in NSW, Queensland, Western Australia and the Northern Territory between 2004 and 2008. Complete national data are not currently available.*

What were the most common causes of cancer death in Aboriginal and Torres Strait Islander males in 2007-2011 (in NSW, Qld, WA, SA and NT)⁶?



What were the most common causes of cancer death in Aboriginal and Torres Strait Islander females in 2007-2011 (in NSW, Qld, WA, SA and NT)⁶?



^{*}UPS stands for Unknown primary site.

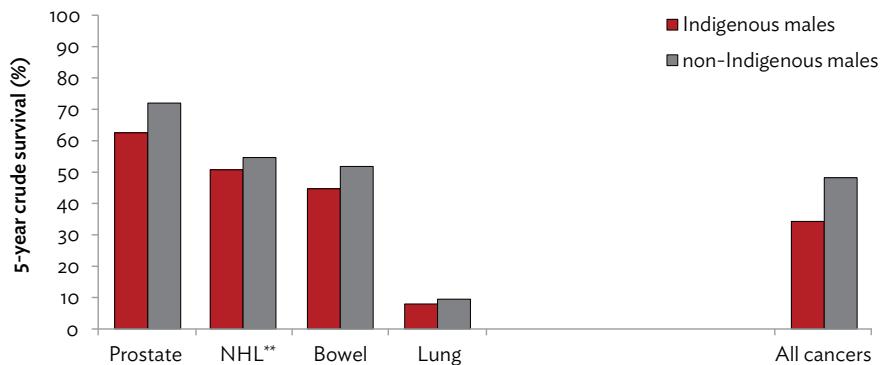
[†] Australian Institute of Health and Welfare 2014. Cancer in Australia: an overview 2014. Cancer series No. 90. Cat. no. 88. Canberra: AIHW.

2.3 Survival from lung cancer

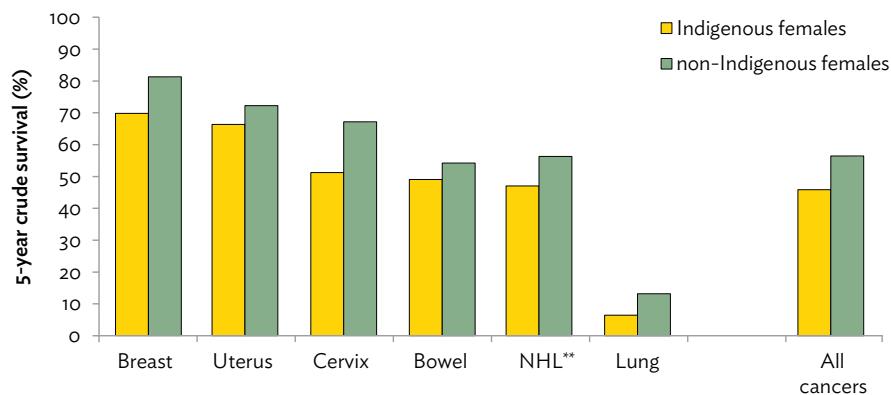
Some facts about lung cancer survival in Aboriginal and Torres Strait Islander people:

- Survival from lung cancer is significantly lower for Aboriginal and Torres Strait Islander people compared with non-Indigenous Australians³
- The lower survival rates for Aboriginal and Torres Strait Islander people with lung cancer may be due to a number of factors, including⁴:
 - higher rates of smoking
 - the likelihood of diagnosis at a later stage of disease
 - lower likelihood of receiving or completing treatment for cancer.

What proportion of Aboriginal and Torres Strait Islander males who were diagnosed with cancer in 1999–2007 survived for at least 5 years (in NSW, Qld, WA and NT)⁶?



What proportion of Aboriginal and Torres Strait Islander females who were diagnosed with cancer in 1999–2007 survived for at least 5 years (in NSW, Qld, WA and NT)⁶?



**NHL stands for Non-Hodgkin lymphoma.

LUNG CANCER IN ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE



Chapter 3

Reducing the risk of lung cancer

3

Chapter 3: Reducing the risk of lung cancer



This chapter provides an overview of risk factors for lung cancer. This chapter also provides information on what Aboriginal and Torres Strait Islander Health Workers can do to increase awareness and reduce the risk of lung cancer in the community.

3.1 Risk factors for lung cancer

The causes of lung cancer are not fully understood. However, it is known that people with certain risk factors are more likely than others to develop lung cancer (Figure 3.1).²

Having risk factors does not necessarily mean a person will develop lung cancer. Many people have at least one risk factor but will never develop lung cancer, while others with lung cancer may have had no known risk factors.

Even if a person with lung cancer has a risk factor, it is often hard to know how much that risk factor contributed to the cancer.²

Figure 3.1 Risk factors for lung cancer

Lifestyle Factors	Environmental factors	Biomedical factors
Tobacco smoking	Passive smoking	Family history of lung cancer
	Air pollution	Previous lung diseases
	Occupational exposure (eg: asbestos)	
		Radon exposure

A risk factor is any factor that is associated with an increased chance of developing a particular health condition. Some risk factors can be controlled or modified, like those related to lifestyle or the environment. Others cannot be controlled or modified, such as family history and inherited factors.^{2,7}

Smoking

There is clear evidence that smoking significantly increases a person's risk of developing lung cancer.

Current smokers are around 9 times more likely to develop lung cancer than people who have never smoked.⁷

Former smokers are almost 4 times more likely to develop lung cancer than people who have never smoked.⁷

In Australia, about 90% of lung cancer in men and 65% in women are estimated to be a result of smoking.⁷

Smoking tobacco is classified as smoking cigarettes, cigars, pipes, bidis and waterpipes.

It does not include exposure to other people's tobacco smoke (known as passive smoking), which will be addressed as a separate risk factor.⁸

Some facts about smoking in Aboriginal and Torres Strait Islander people:

- Smoking is responsible for one in five of all deaths in Aboriginal and Torres Strait Islander people⁴
- In 2010, Aboriginal and Torres Strait Islander people were more than twice as likely as non-Indigenous Australians to smoke tobacco⁴
- Daily smoking rates in Aboriginal and Torres Strait Islander people has declined from 51% in 2002 to 41% in 2013⁸
- In general, Aboriginal and Torres Strait Islander people:
 - take up smoking at an earlier age than non-Indigenous Australians
 - continue to smoke for longer than non-Indigenous Australians.

Passive smoking

Although active smoking increases the risk of lung cancer more than passive smoking, there is still a significant risk of developing lung cancer due to passive smoking.

Passive smoking is most common in places where smoke may be trapped or poorly circulated, such as indoors and in cars. Before smoking bans were introduced in indoor public places, smoking was permitted in restaurants, bars and a variety of other indoor areas. People who visited or worked in these places may have been exposed to passive smoking. Exposure can also happen at home if people smoke inside the house.²

Passive smoking is being exposed to tobacco smoke, or the chemicals in tobacco smoke, without actually smoking.²

Some facts about passive smoking in Australia:

- Women who are exposed to their partner's smoking are 30% more likely to develop lung cancer than people who are not exposed⁷
- People who are exposed to passive smoking in the workplace are twice as likely to develop lung cancer.⁷

Family history

A person who has a family member with lung cancer (mother, father, brother or sister) is around twice as likely to develop lung cancer as someone without a family history of the disease. This risk also appears to be more significant if two or more family members have had lung cancer or if a person's mother had lung cancer.⁷

The increased risk of developing lung cancer for people with a family history may be due to shared genetic traits. It may also be the result of shared environmental and lifestyle similarities.

Other environmental and occupational risk factors for lung cancer

Smoking is by far the greatest risk factor for lung cancer. However, some chemicals in the environment or the workplace have been shown to increase the risk of developing lung cancer (Table 3.1).⁷ Smoking can also interact with some of these chemicals to further increase the risk.⁷

Table 3.1 Chemicals that may increase risk of lung cancer

Chemical	Who might be exposed
Radon	People who work in uranium mines
Arsenic	People who work in mining and metal-manufacturing
Polycyclic aromatic hydrocarbons	Smokers, people exposed to urban and industrial air pollution
Cadmium	People who work in cadmium alloy production, mechanical plating, zinc smelting, cadmium-silver alloy soldering and poly-vinyl chloride compounding
Asbestos	People who work in asbestos mines, manufacturers of asbestos building products, builders and people renovating old homes
Silica	People who work in mining, quarrying and in the granite, ceramic and steel industries
Iron and steel founding	People who work in the production processes of iron and steel founding
Nickel	People who work with nickel, including smelter workers, nickel rosters and nickel electrolysis workers
Beryllium	People who work in mining and metal manufacturing
Paint	People who work with paint every day as their occupation
Chromium VI	People who work in the production, use and welding of chromium-containing alloys such as stainless steel and high-chromium steel, and people who work with chromium-containing paints, such as in the aerospace, construction and maritime industries
Air pollution	People living in urban and industrial areas may be more exposed than people living in rural areas

3.2 Reducing the risk of lung cancer

Addressing modifiable risk factors, such as smoking, can help reduce the risk of developing lung cancer. Smoking and passive smoking are the major modifiable risk factors for lung cancer. Quitting smoking can reduce this risk substantially.

How to help people quit smoking

It is important that health professionals take every opportunity to provide education about the harmful effects of smoking and to provide advice and support to help people quit smoking.¹

All people who smoke should be offered advice and/or treatment for quitting that is appropriate to their own personal situation.¹ Effective quitting smoking methods include targeted counselling and medication.

For people who are exposed to passive smoking, it may be useful to have a discussion on strategies to reduce this exposure, such as ensuring that smoking does not occur in the home.⁹

Some facts about quitting smoking

- Smoking is addictive. This is the main reason smokers continue to smoke even though many have tried to quit. It is important to remember this when you work with people who are (or were) smokers.
- Seeing people smoke regularly, and knowing people who smoke, can make smoking seem normal. This can sometimes make it harder for someone to quit smoking.
- Factors that can make it hard for Aboriginal and Torres Strait Islander people to quit include:
 - having a poor knowledge of the harmful effects of smoking
 - being less likely to access to services that can help with quitting smoking, compared with non-Indigenous Australians.

Services to help quit smoking

Quitlines: People who work at telephone-based Quitlines and other services have been trained to deliver services to help people to quit smoking, including people from Aboriginal and Torres Strait Islander communities. It may be useful to refer your patients to these services. The Quitline can be accessed by calling 13 QUIT (13 78 48).

icanquit: This online service provides methods to quit, how to get started and how to stay quit from smoking. The online service allows for interaction with others trying to quit, support resources including a savings calculator and the ability to track your quitting journey. The service can be found at www.icanquit.com.au/.

Patches: Under the Australian Government Pharmaceutical Benefits Scheme, Aboriginal or Torres Strait Islander people qualify for up to two free 12-week courses of nicotine patches per year. Participation in a support and counselling program is recommended but not mandatory in order to qualify for this scheme.⁹

Nicotine Replacement Therapy (NRT): Patches, gum, inhaler and lozenges are available by prescription to Aboriginal and Torres Strait Islander people who have registered with their local health service to participate in the Indigenous Health Incentive scheme under the Practice Incentives Program (PIP).

3.3 The importance of lung cancer early detection

Early detection of lung cancer can help to improve treatment outcomes and survival.⁹

For some cancers, such as breast cancer, bowel cancer and cervical cancer, population-based screening programs are available to help find the cancer early. There are currently no population-based screening programs for lung cancer in Australia.

Improving community awareness about the risks and symptoms of lung cancer, and the importance of seeing a doctor about these symptoms, can lead to detection and improved outcomes for people diagnosed with this disease.⁹

Diagnosis of lung cancer can be delayed by a number of factors, including:

- the symptoms of lung cancer can be difficult to identify, or ‘non-specific’ such as a cough
- people may be ashamed or embarrassed to visit their doctor when they have symptoms
- some people may not be aware that lung cancer can occur in non-smokers.³

Chapter 4 provides more information on the symptoms of lung cancer and the steps needed to be taken to investigate these symptoms.

Chapter 4

4

Investigating and diagnosing lung cancer

Chapter 4: Investigating and diagnosing lung cancer



This chapter describes the symptoms of lung cancer and the steps that need to be taken to investigate these symptoms.

4.1 Symptoms of lung cancer

Many symptoms of lung cancer are non-specific. This means they are symptoms that are common to other conditions as well. As a result, people may not visit their doctor to discuss these symptoms, which can delay diagnosis of lung cancer.

The symptoms of lung cancer can include:¹⁰

- a new or changed cough
- coughing up blood
- a chest infection that won't go away
- chest pain and/or shoulder pain
- shortness of breath
- hoarse voice
- weight loss or loss of appetite.

Having any one of these symptoms does not necessarily mean that a person has lung cancer. However, if any of the symptoms above occur for more than three weeks (or less than three weeks in people with known risk factors – particularly smokers), urgent assessment is required.² Being aware of the symptoms of lung cancer is important. The earlier lung cancer is found, the better the chance of survival.

4.2 How is lung cancer diagnosed?

Patients should be referred to a doctor as soon as possible if they have any symptoms of lung cancer.

Investigation of lung cancer symptoms by a doctor

Tests the doctor may do to investigate these symptoms are listed in Table 4.1.^{1,3,10}

Table 4.1 Tests to investigate lung cancer conducted or ordered by a doctor

Tests	What this involves
History and physical examination	<ul style="list-style-type: none"> A doctor will ask questions about the person's symptoms and their general health A doctor will perform a physical examination. This examination may involve the doctor listening to a person's chest.
If the doctor suspects lung cancer, a person will be urgently referred for imaging tests	
Chest X-ray	<ul style="list-style-type: none"> A chest X-ray is the recommended first line of investigation that is performed Small tumours may not show up on an X-ray The doctor may review previous chest X-rays and imaging tests at this time <ul style="list-style-type: none"> Aboriginal Health Workers can remind patients to take any previous X-rays with them to their appointment.
Chest computed tomography (CT) scan¹	<ul style="list-style-type: none"> If required, a chest CT scan is the recommended second line of investigation for lung cancer following a chest X-ray A chest CT scan can show smaller tumours than those found by chest X-rays A chest CT scan can also show more detailed information about the tumour and provides information about lymph nodes in the chest and other organs.

Specialist tests to investigate symptoms of lung cancer

If tests performed by the doctor show results that suggest a person may have lung cancer, the person will be referred urgently to a specialist doctor, such as a respiratory physician.

The specialist will perform a number of tests to confirm the diagnosis of lung cancer (Table 4.2).²

Table 4.2 Tests conducted or ordered by a specialist doctor to confirm a diagnosis of lung cancer

Test	What this involves
Bronchoscopy	<p>A bronchoscopy is a special test that allows the doctor to look directly into a patient's airways using a tiny camera.</p> <p>To prepare for the test, the patient will be given some medicine to help them relax. They will also be given a spray on the back of their throat to help numb the area.</p> <p>During the test, the doctor will then insert a flexible tube called a bronchoscope through the patient's nose or mouth and down their throat into their airways.</p> <p>During the bronchoscopy, the doctor will take a tissue sample (known as a biopsy).</p>
Biopsy	<p>A biopsy is one way of collecting a tissue sample that can then be tested to see if a person has lung cancer.</p> <p>A biopsy can be taken during the bronchoscopy (see above) or it might be taken using a fine needle inserted into the patient's chest.</p> <p>If a fine needle is used to take a biopsy, the doctor will use an X-ray machine to ensure the needle is being inserted into the correct place where the tumour is suspected.</p>

Positron emission tomography (PET) scan	A positron emission tomography (PET) scan is a special body scan used to see whether lung cancer has spread to other parts of the body.
	To prepare for the scan, the patient will be injected with a radioactive sugar fluid. It takes 30–90 minutes for the fluid to go through the body. The patient will then be ready to have a body scan.
	The scan shows ‘hot spots’ in the body where there are active cells, such as cancer cells. All active cells are not necessarily cancer cells. The scan will be carefully evaluated by a specialist to identify any cancer cells.

Figure 4.1 Investigations and diagnostic tests for lung cancer.

Person goes to the doctor with possible symptoms of lung cancer
Doctor conducts a physical examination

If symptoms are persistent and suggestive of lung cancer,
doctor will refer for urgent imaging tests



Person has a chest X-ray and sometimes a chest CT scan

If imaging results are abnormal, patient will be referred to a respiratory physician or specialist with expertise in lung cancer



Specialist conducts additional tests to confirm a diagnosis of lung cancer, including:

- **bronchoscopy**
- **biopsy**
- **positron emission tomography (PET) scan**

Adapted from Cancer Australia. *Investigating symptoms of lung cancer: a guide for GPs*, 2012.

4.3 Test results and what they mean

If lung cancer is diagnosed, decisions about treatment options are based on information from the patient's history, imaging tests and biopsies as well as the patient's general health and preferences.

It is important to understand what the various test results mean and how they can be used to inform the decision-making process.

Pathology and imaging reports¹¹

Pathology and imaging reports provide important information about lung cancer based on test results, including:

- the type of tumour (i.e. non-small cell or small cell lung cancer)
- the size of the tumour
- the location of the tumour
- whether lung cancer has spread to other parts of the body.

Staging lung cancer^{1,12}

The staging category of lung cancer is worked out using the patient's history, imaging results and biopsy information.

Table 4.3 provides a simplified overview of staging for non-small cell and small cell lung cancer.¹² Small cell lung cancer is sometimes staged more simply as shown in Table 4.4.¹

Staging is a way of describing cancer and how much it has spread in the body.

Table 4.3 Non-small cell lung cancer staging

Stage I	Cancer only in one lobe of the lung and less than 5cm in size
Stage II	Cancer in the lung, with spread to nearby lymph nodes, or cancer more than 5cm, or that has grown into the chest wall
Stage III	Cancer has spread to lymph nodes in the centre of the chest or there are tumours in more than one lobe
Stage IV	Cancer has spread to distant parts of the body, e.g. brain or bones

Table 4.4 Small cell lung cancer staging

Limited disease	The tumour can be found in only one lung and nearby lymph glands
Extensive disease	The tumour has spread outside one lung or to other parts of the body

Dealing with stigma¹³

In health and health care, stigma can occur when the community holds a stereotypical or negative attitude towards a certain disease.

Unfortunately, stigma can be part of the lung cancer experience. This is largely due to its association with smoking.

The stigma associated with lung cancer can add to psychological distress for patients and can have a poor effect on their quality of life. In some cases, patients may experience feelings of guilt, blame and shame about being diagnosed with lung cancer.

Another form of stigma for lung cancer is the community believing that lung cancer is mostly fatal, even with treatment. It may mean that people delay having treatment because they feel that it is not worthwhile.

4.4 The role of the Aboriginal and Torres Strait Islander Health Worker

Being tested for, and diagnosed with, lung cancer can be a frightening and confusing time.

What your patients may be feeling or experiencing

- Patients may be reluctant to visit their doctor if they have symptoms of lung cancer. This may be due to a mistrust of unfamiliar health care professionals, or it may be because they feel ashamed or embarrassed due to having a history of smoking
- Patients from regional, rural or remote communities may need to travel to a city for testing and diagnosis. This is because the technology and machines used to perform the tests and scans to diagnose lung cancer may not be available in some regional, rural and remote areas
- Patients may feel confused or intimidated by the complicated medical language used by doctors during diagnosis.

How you can help

As an Aboriginal and Torres Strait Islander Health Worker, your role may include:

- encouraging people to report symptoms
- increasing awareness of the importance of early detection
- providing early referral for diagnostic testing
- providing practical support for patients who need to travel from regional, rural or remote communities to undergo testing
- helping patients explain their diagnosis to their family and community.

Practical support for travel

If a person needs to have tests in a hospital that is far away from home, they may be able to get help with the cost of accommodation and travel.

Each State and Territory has a Government-funded scheme to help patients who have to travel. If you enter ‘Transport assistance for health’ in your web browser, a variety of schemes will be provided. Some of these include:

- Transport for Health (Australia wide)
- Patient-Assisted Transport Scheme (PAT'S) (South Australia)
- Isolated Patient Transport and Accommodation Assistance Scheme (IPTAAS) (NSW).

Some people may be eligible for assistance with childcare, meals, home help and sickness allowance. It may also be helpful to encourage a person to bring a family member, friend or community member to provide some company and emotional support.

Explaining a diagnosis of lung cancer

The concept of cancer may be poorly understood in Aboriginal and Torres Strait Islander communities.

It is important to explain that having a diagnosis of lung cancer is not a ‘death sentence’.

You can educate patients and their family and carers that effective treatments for lung cancer are available and these are improving all the time.³

Chapter 5

Multidisciplinary team approach to care

5

Chapter 5: Multidisciplinary team approach to care



This chapter explains the importance of multidisciplinary care for lung cancer. It outlines the role of the Aboriginal and Torres Strait Islander Health Worker within the multidisciplinary health care team.

5.1 Multidisciplinary care

Treatment and supportive care for people with lung cancer involves a number of different medical, nursing and allied health professionals working together as a team. This team approach is called multidisciplinary care.

Studies in different types of cancer have shown that multidisciplinary care can improve¹⁰:

- survival
- patient satisfaction and quality of life
- care in accordance with the best and latest evidence recommended
- the timeliness of treatment.

Multidisciplinary care involves different health professionals working together to discuss treatment options and develop an individual treatment plan for each patient.

Cancer Australia has developed a set of principles of multidisciplinary care. The principles recognise that treatment and care for people with cancer may be delivered differently in different services and locations, but highlight the common essential elements.¹⁵

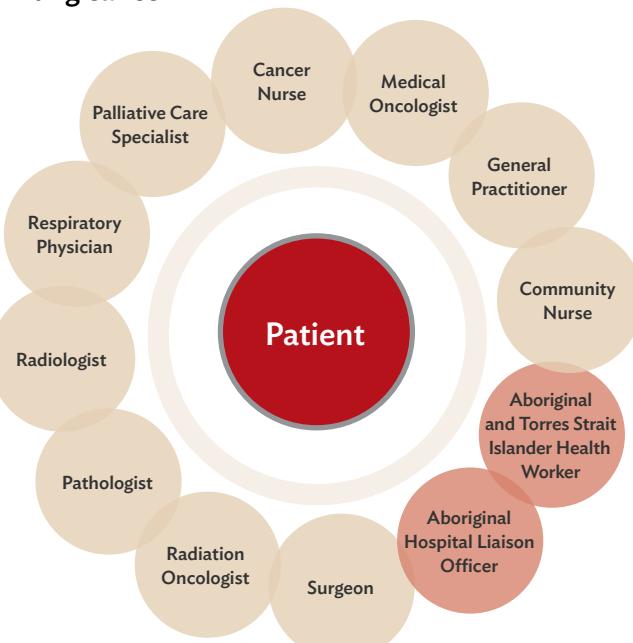
Principles of multidisciplinary care¹⁴

- A team approach, involving core disciplines integral to the provision of good care, including general practice, with input from other specialties as required
- Communication among team members regarding treatment planning
- Access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution
- Provision of care in accordance with nationally agreed standards
- Involvement of patients in decisions about their care.

5.2 The multidisciplinary team

A number of health professionals are involved in treating and supporting a person with lung cancer. Figure 5.1 shows some of the key health professionals who may be involved in the lung cancer pathway. Aboriginal and Torres Strait Islander Health Workers are important members of this team.

Figure 5.1 The key health professionals involved in the treatment of a person with lung cancer



MULTIDISCIPLINARY TEAM APPROACH TO CARE

The lung cancer multidisciplinary team (MDT) includes core disciplines who must be involved in treatment planning, and other health professionals who may be involved in the patient's treatment and care at different times throughout the journey.

A list of health professionals and the role they play in the lung cancer MDT is provided in Table 5.1.

Table 5.1 Members of the lung cancer multidisciplinary team	
Team member	Role
Core team	
General practitioner (GP)	Provides ongoing care and works with other members of the treatment team
Cancer nurse	Specialises in providing information and supporting people with cancer
Medical oncologist	Specialises in cancer drugs such as chemotherapy and targeted therapies
Palliative care physician	Specialises in providing practical support and symptom relief
Pathologist	Examines cells, tissue and blood from the body
Radiologist	Examines scans, x-rays and other imaging tests
Radiation oncologist	Specialises in radiotherapy (X-ray treatment)
Respiratory physician	Specialises in investigating and treating lung diseases, including lung cancer
Thoracic surgeon	Specialises in lung cancer surgery, including biopsies
Other team members	
Aboriginal and Torres Strait Islander Health Worker	Provides specialised healthcare and practical support information in a culturally appropriate way
Aboriginal Liaison Officer	Provides access to mainstream health care services to increase the cultural awareness and sensitivity of health care services

Cancer Care Coordinator	Provides support and information to patients and their families
Community/district nurse	Provides care and support for people at home
Community palliative care team	Provides practical support and symptom relief at home
Dietician	Specialises in providing advice about what to eat
Pastoral care/religious representative	Provides spiritual support
Pharmacist	Specialises in supplying, dispensing and manufacturing drugs
Physiotherapist, occupational therapist, exercise physiologist	Assists with exercise and pain management
Psychologist, psychiatrist or counsellor	Specialises in providing emotional support and managing anxiety and depression
Radiation therapist	Assists in planning and giving radiotherapy
Research nurse	Assists in the planning and coordination of clinical research studies and clinical trials
Social worker	Specialises in providing emotional support, counselling and advice about some practical and legal matters
Welfare worker	Provides practical support and advice

5.3 Multidisciplinary team meetings

During the MDT meeting, health professionals will review:¹⁵

- the patient's history and general health
- the patient's imaging and pathology results
- the patient's supportive care needs
- the patient's treatment options.

Multidisciplinary team meetings include core MDT members, and other health professionals to discuss individual patients and agree on a treatment plan.

MDT meetings may be held face-to-face, or via teleconference or videoconference if team members are in different locations.³

The team will then agree a treatment plan to be discussed with the patient and sent to the patient's GP. Once agreed, the treatment plan is then sent to all members of the MDT.

5.4 The role of the Aboriginal and Torres Strait Islander Health Worker

As an Aboriginal and Torres Strait Islander Health Worker you can use your knowledge and understanding to help inform the treatment plan.

Talking to the MDT and other health professionals

You may need to talk to and work with the MDT when a person is receiving hospital-based treatment, follow-up treatment, or when they go back to their community.

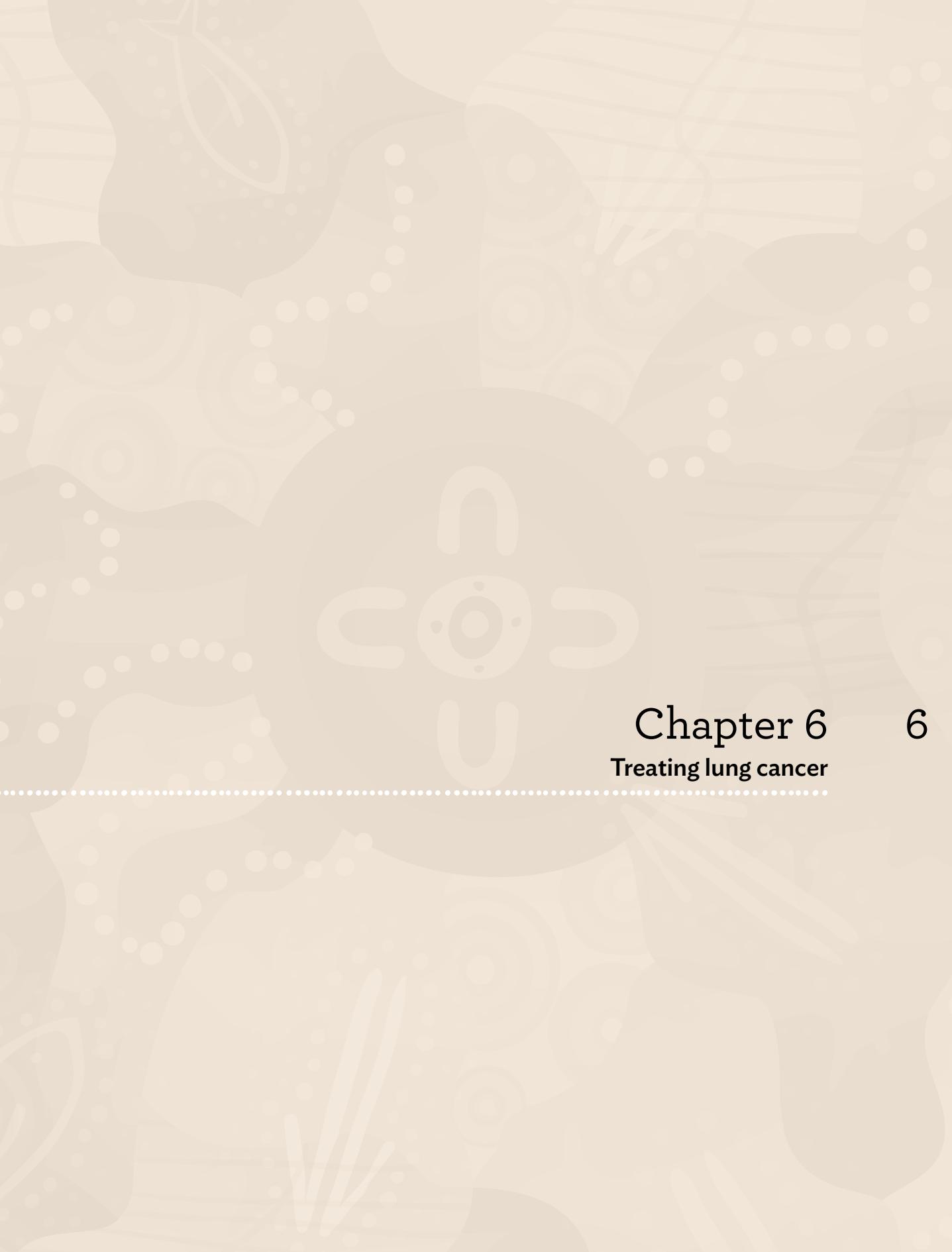
Part of your role may be to provide guidance and information on social and cultural issues.

Talking to the patient

The health professionals involved in the patient's care may change at different points in the cancer journey. This can be quite daunting for the patient.

Part of your role may be to help the patient understand the job of each health professional involved in their care.

You may also act as a central contact person for the patient at each stage of the pathway.



Chapter 6

Treating lung cancer

6

Chapter 6: Treating lung cancer



This chapter provides an overview of treatment options available for lung cancer, including surgery, radiotherapy, chemotherapy and targeted therapies. The important role of palliative care is also discussed.

6.1 Treatment options for lung cancer

The main treatment options for lung cancer are surgery, radiotherapy and systemic (whole of body) therapies, such as chemotherapy and targeted therapies.^{1,3} Each treatment is described in more detail in this chapter.

Aboriginal and Torres Strait Islander Health Workers are crucial in providing information and support for Aboriginal and Torres Strait Islander people undergoing treatment for lung cancer.

Having treatment for lung cancer can be a worrying time. Your patients may experience a range of different feelings, such as:

- **Confused about their treatment options and potential side effects.** Misconceptions about treatment can lead to people not undertaking or completing treatment for lung cancer. Aboriginal and Torres Strait Islander people are less likely to complete treatment for cancer than non-Indigenous Australians. This is true across all treatment types including surgery, radiotherapy and chemotherapy. This contributes to poorer outcomes.¹⁶
- **Uncomfortable about being in a hospital, or being treated by unfamiliar health professionals.** Many Aboriginal and Torres Strait Islander people may be reluctant to go to hospital to have treatment for lung cancer. Some Aboriginal and Torres Strait Islander people may feel uncomfortable being treated by health professionals of the opposite gender.³

As an Aboriginal and Torres Strait Islander Health Worker, your role may include:

- helping patients and their families to understand and decide about their treatment choices
- providing cultural advice to health professionals.

It is important that you understand the main treatment options for lung cancer, what is involved and what the possible side effects might be.

Planning treatment

The decision about which treatment(s) to recommend for a patient will depend on a number of things, including:

- the type and severity of the cancer (see Table 6.1)¹
- the patient's age
- the patient's breathing capacity and ongoing general health
- the patient's personal preferences, including spiritual and cultural values
- the patient's family and kinship obligations.

Table 6.1 Treatment for lung cancer, by cancer type

Non-small cell lung cancer	Small cell lung cancer
Best treated with surgery, where possible	Usually treated with chemotherapy.
Otherwise, a combination of radiotherapy and chemotherapy is usually recommended	Some people with cancer in one lung will also have radiotherapy to the chest and brain (this is known as preventive or prophylactic radiotherapy).
	Surgery is not often used for this type of cancer because it usually spreads early.

Respecting patient choice

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Sometimes, a person may choose to not have treatment for lung cancer. It is important that a person who chooses not to have treatment for lung cancer is still offered supportive care. This can involve visiting the doctor to review and relieve their symptoms.

Section 6.7 and Chapter 9 provide more information on palliative care.

Aims of treatment for lung cancer

The aim of treatment for lung cancer can be to remove the cancer, to slow the growth of a lung cancer and/or to manage the symptoms of lung cancer.

Different treatments are used depending on the aim of treatment. It is important that patients understand the aim of the treatment(s) recommended for them. Patients should also be told about the likely benefits and risks of a treatment before treatment starts.³

Side effects of treatment

The **specific physical side effects** of different lung cancer treatments are discussed in this chapter.

When reading about side effects, it is important to remember that everyone responds differently to treatment. Some side effects happen to most people, while others happen only occasionally. Some side effects happen straight away, while others take longer to develop.

In most cases, medicine can be prescribed to make any side effects less severe.¹

As an Aboriginal and Torres Strait Islander Health Worker, you will play an important role in:

- supporting patients as they experience side effects of treatment, and
- explaining these to the family.

Patients should be encouraged to talk to their medical team if they have any side effects of treatment for lung cancer.¹

More information about **general physical side effects** associated with lung cancer, as well as information on emotional and practical support needs can be found in Chapter 7 of this handbook.

Involving the patient, family and community in treatment decision making

There are a lot of factors that influence a person's decisions about treatment. Close family and/or community members can be a helpful source of support for a person when they are making a decision about their treatment. Involving close family or community members can help both the health professionals and the family.

Treatment adherence among Aboriginal and Torres Strait Islander people

Adherence to lung cancer treatments may be poor among Aboriginal and Torres Strait Islander people. This may be due to:¹⁷

- unfamiliar treatments with unpleasant side effects
- poor understanding of the benefits of treatment
- pressure to meet community responsibilities
- the need to travel for treatment
- being away from family and community for long periods of time.

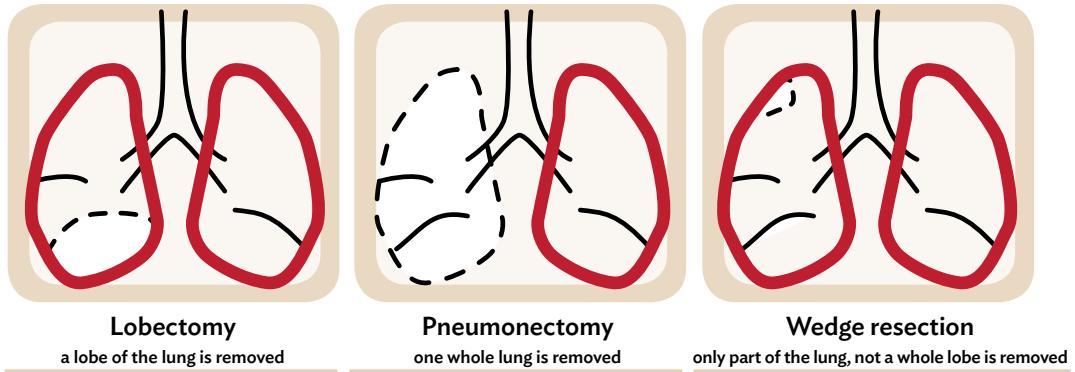
The Aboriginal and Torres Strait Islander Health Worker can play a key role in helping a person understand the benefits of treatment, possible side effects and how these are managed, as well as ensuring the patient is supported if travel from home is required. This may improve adherence to treatment.¹

6.2 Surgery

Surgery to remove part or all of the lung is the treatment of choice for people who have early-stage, non-small cell lung cancer. Surgery is rarely used in the treatment of small cell lung cancer.^{1,3}

There are several different types of lung surgery, as shown in Figure 6.1. The surgeon will recommend the type of operation depending on the location and spread of the lung cancer.

Figure 6.1. Types of lung surgery



What does surgery involve?

Surgery for lung cancer requires a patient to have a general anaesthetic (when the patient is put into a deep sleep). Lung cancer surgery is usually done through an incision between the ribs.

When a patient wakes up after surgery, they will have tubes coming out of their chest. These tubes help to drain excess fluid and air from the lungs, and will be removed once drainage is complete.

The patient will usually remain in hospital for five to seven days after the operation.

Fast fact

Smoking can increase a patient's risk of having complications from surgery.¹ Advise patients to stop smoking as soon as they are diagnosed with lung cancer.

Side effects of surgery

Side effect	What causes it?	What can help?
Pain/discomfort	Can occur due to the incisions made during surgery	The patient's health care team will work with the patient to reduce these effects using pain-relief medicine. ¹
Breathlessness	Removal of part or all of a lung	Exercising may help to reduce this symptom. ¹
	Poor lung function before surgery	A physiotherapist and other members of the health care team can assist and advise about appropriate exercises.

6.3 Radiotherapy

Radiotherapy treats cancer using targeted X-ray beams to destroy cancer cells. Radiotherapy is a localised treatment, which means that it only treats the area of the body it is aimed at.¹

When is radiotherapy recommended?

Radiotherapy may be offered when lung cancer cannot be managed by surgery and has not spread outside the chest.¹ Radiotherapy involves multiple treatments over an extended period of time. Radiotherapy treatment will vary but regularly occurs once a day, five days per week for 3 – 6 weeks.¹⁸

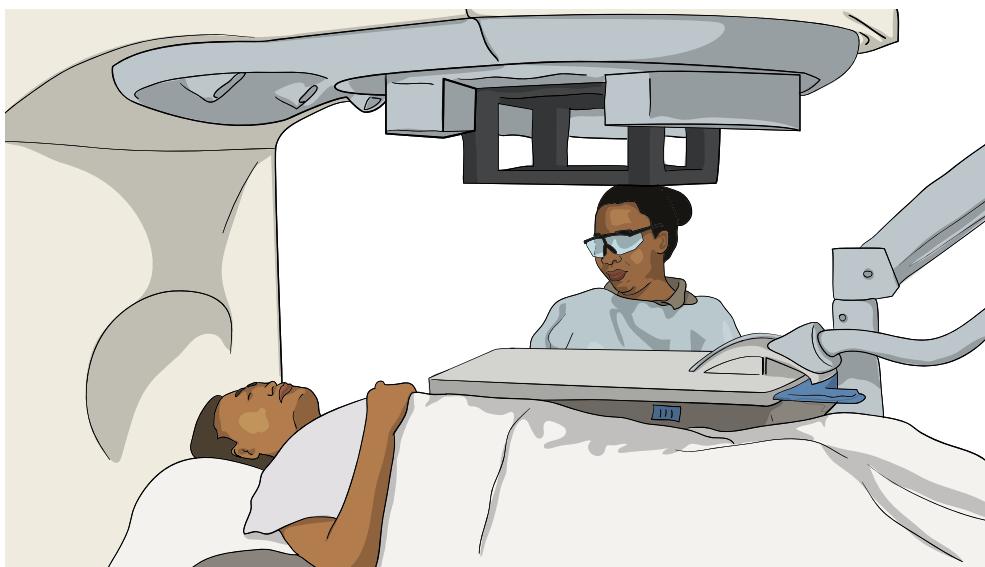
Radiotherapy can also be used:¹

- to treat an early-stage, small, peripheral cancer (i.e. on the outer areas of the lung rather than deep inside) if the patient is not fit for an operation
- after surgery to destroy any cancer cells that may still be present
- as palliative treatment, to reduce symptoms, to improve quality of life or to extend life.

TREATING LUNG CANCER

When planning radiotherapy treatment, the patient's doctor will take a chest X-ray, chest CT scan or PET scan of the treatment area. To ensure that the same area is treated each time, the radiation therapist will make a few small marks on the skin.¹

During treatment, the patient will lie on a treatment table. A machine that delivers the radiation will be positioned around them. Each treatment only takes a few minutes but the treatment session, including placement of the patient, will usually take longer. Radiotherapy treatment is painless and the patient will be made as comfortable as possible.¹



Side effects of radiotherapy

The side effects of radiotherapy depend on the area of the body being treated and the dose of radiation.

Side effect	Details	What can help?
Skin rashes	<p>Patients who have radiotherapy to the chest may experience a mild reaction on the skin, like sunburn.</p> <p>Things that can make skin reactions worse include:</p> <ul style="list-style-type: none"> - having chemotherapy at the same time as radiotherapy - having other health problems, such as diabetes - having sun-damaged skin - smoking. 	<p>Washing with a mild soap or cleanser and using a light moisturising cream.</p> <p>Wearing sun protective clothing or using sunscreen over the treated area when in the sun.</p> <p>Avoiding irritants by protecting the skin from damage by abrasion (e.g. shaving with a wet razor), chemicals (e.g. perfumes, deodorants, hair dyes) and temperature extremes.</p> <p>Keeping skin folds dry.</p>
Difficulty swallowing	<p>Patients who have a long course of radiotherapy (i.e. several weeks) may have temporary difficulty and pain on swallowing. This is because the oesophagus or food pipe can become inflamed, a condition known as oesophagitis.</p>	<p>Eating soft food or a liquid diet can be helpful.</p> <p>Symptoms are likely to improve once treatment is over.</p> <p>It is advisable to let the doctor or nurse know as soon as these symptoms arise as they can provide medicines to make it better.</p>

Shortness of breath	Any radiotherapy to the lungs will cause some scarring, which can only be seen on X-rays or CT scans after treatment. Some patients experience temporary shortness of breath in the weeks after the radiotherapy has finished.	This usually improves by itself, or may require treatment with medicine. ¹
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6.4 Chemotherapy

Chemotherapy uses drugs to destroy cancer cells (cytotoxic drugs).

Chemotherapy works by killing cells that are rapidly dividing, such as cancer cells. Chemotherapy also kills normal cells that are rapidly dividing. However, unlike cancer cells, normal cells can repair the damage and recover. The aim of chemotherapy is to kill cancer cells while doing the least possible damage to healthy cells.¹

When is chemotherapy recommended?

Chemotherapy is commonly given to patients whose cancer is large or has spread outside the lungs. It may be given:¹

- before surgery, to try to shrink the cancer and make the operation easier (neoadjuvant treatment)
- before or during radiotherapy, to increase the chance of the radiotherapy working (chemo-radiation)
- after surgery, to reduce the chance of the cancer coming back
- as palliative treatment, to reduce symptoms, improve quality of life or to extend life.

What does chemotherapy involve?

Generally, chemotherapy is administered intravenously (meaning into a vein in the arm, hand or chest) through a drip or a plastic tube, known as a catheter. It is given in ‘cycles’ that typically last three weeks each. Each cycle involves a short period of treatment followed by a rest period in which the patient does not receive treatment.

The number of treatments a person has will depend on the type of lung cancer and how well their body is handling the side effects.¹

Some types of chemotherapy are given by mouth (i.e. in tablet form). If chemotherapy is given using tablets, it may be given on a continual daily basis rather than in cycles.¹



Side effects of chemotherapy

Most drugs used in chemotherapy cause side effects, and most of these side effects can be managed. Patients should be encouraged to talk to their doctor if they experience any side effects when receiving chemotherapy. Suggestions about how to manage some of the more common side effects are listed below.

Side effect	Details	What can help?
Nausea and/or vomiting	Common side effects of chemotherapy	Usually controlled using anti-sickness medicines known as anti-emetics. These are generally given at the same time as chemotherapy, and the first two to four days afterwards. It can also help to make dietary changes, such as eating small, more frequent meals, cutting down on fried and fatty foods and drinking plenty of fluid.
Mouth ulcers	Can develop due to chemotherapy Can be painful and can affect what and how much a patient can eat	Encouraging patients to take extra care of their mouth during chemotherapy. Treatments available to help patients manage the pain associated with mouth ulcers. Brushing teeth and gums with a very soft brush after every meal to prevent infection. Using an analgesic gel from the chemist or sodium bicarbonate mouthwash to alleviate discomfort. Warm salt water can also help to keep the mouth clean and reduce the risk of developing mouth ulcers.

Fatigue	<p>Common side effect of chemotherapy and can last three to six months after treatment is over</p> <p>Can be caused by a number of factors including low levels of red blood cells, changes in metabolism, side effects of treatment, depression or sleeping difficulties.</p> <p>If fatigue is due to anaemia (i.e. low levels of red blood cells) caused by chemotherapy, the treating doctor may recommend a blood transfusion.</p> <p>Light exercise can help to reduce fatigue caused by chemotherapy and other treatments; gentle exercise such as walking is ideal.</p>
Thinning or loss of hair	<p>Can range from mild thinning to total hair loss, including body hair</p> <p>Although losing hair may not seem serious compared with coping with lung cancer, many people find it distressing. For example, losing hair may affect a person's feelings about themselves and their sexuality</p> <p>Use a soft hairbrush.</p> <p>Consider cutting the hair short if this is less upsetting than allowing it to fall out.</p> <p>Consider speaking with your oncology nurse or doctor, or contact the Cancer Council Helpline on 13 11 20 about accessing a wig, turban or hat.</p>

Skin reactions	<p>May include redness, itching, peeling, dryness or acne</p> <p>Some chemotherapy drugs can also make skin more sensitive to the sun</p>	<p>Patients should avoid being in the sun for long periods, and use sunscreen when outdoors.</p> <p>Consider using moisturising creams, vitamins and medicines that can help with skin changes; a doctor or pharmacist can provide advice on the best products to use.</p> <p>Wear sun protective clothing or use sunscreen when in the sun.</p> <p>Avoid irritants such as perfumes, deodorants, hair dyes or hair spray.</p> <p>Keep skin folds dry.</p> <p>Keep well hydrated.</p> <p>Avoid extreme weather conditions like severe cold and hot weather that can aggravate dry skin.</p> <p>Wash clothes in mild detergent that are labelled allergen-free or unscented.</p>
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An important note about infection

Chemotherapy temporarily weakens the immune system, so patients may have trouble fighting infections like a cold or flu while they are receiving treatment.

Any infection during chemotherapy can be serious and potentially life-threatening. Infections can be treated effectively using antibiotics.

You should advise patients to be aware of the following symptoms of an infection:

- fever (a temperature above 38°C)
- chills
- severe sweats.

If these symptoms develop, patients should seek immediate medical advice, as strong antibiotics will be required.

Other symptoms of infection include:

- loose bowels
- a burning sensation when urinating
- severe cough or sore throat
- unusual vaginal discharge or itching
- redness, swelling or tenderness around a wound, sore, pimple, boil or the site drip for chemotherapy.

6.5 Targeted therapies

Recent research has discovered that the growth of some lung cancers depends on the presence of damaged genes (known as mutations) in the cancer cells. The cause of the mutations is unknown.¹

A number of drugs have been developed to ‘switch off’ these mutations, which can stop or slow the growth of the cancer. Because these drugs target specific mutations within the cancer, they are known as ‘targeted therapies’.¹

Two mutations found in lung cancer are the EGFR and ALK mutations. If your patient’s doctor suspects that lung cancer may be due to one of these mutations, the doctor will send a sample of the tumour for testing in a laboratory. If one of the mutations is found, this will guide the doctor in the choice of targeted therapy for your patient’s particular cancer.¹

Other examples of targeted therapies are drugs that attack the cancer’s blood supply. These drugs, known as anti-angiogenesis drugs, work by starving the cancer.¹

Side effects of targeted therapies

Targeted therapies typically have fewer side effects.¹ This is because they are restricted to targeting the specific damaged genes or mutations within the cancer.

6.6 Complementary therapies and traditional Aboriginal and Torres Strait Islander medicine

Complementary therapies are treatments or therapies that can be used alongside conventional treatments to enhance quality of life and improve overall wellbeing. Examples can include relaxation therapy and meditation.

Alternative therapies are treatments that are used *instead of* conventional treatments. There is no evidence to support the use of alternative therapies in the treatment of lung cancer.

Traditional Aboriginal and Torres Strait Islander medicine (bush medicine) may be used by people as a complementary therapy alongside conventional treatments or as an alternative therapy instead of conventional treatments. In some parts of Australia, bush medicine is still widely used by Aboriginal and Torres Strait Islander people.

It is important for patients to understand that some complementary therapies can reduce the effectiveness of conventional treatments. It is very important that the treating doctors are aware if any bush medicine or other complementary medicines are being used.



The role of the Aboriginal and Torres Strait Islander Health Worker

It is important for Aboriginal and Torres Strait Islander Health Workers to encourage patients and their families to talk to their doctors about any traditional bush medicines they may be using.

You can also encourage open communication about traditional bush medicine between patients and their health team. This can assist the treating doctor in making a comprehensive assessment of the patient in developing their treatment plan.

6.7 Early integration of palliative care

Palliative care is the holistic care of people with a life-limiting illness, as well as their families and carers. It aims to improve the quality of life of people with cancer and their families by preventing and relieving symptoms of cancer or cancer treatment. It also involves the management of other physical and emotional symptoms, and works to address any practical problems that may be experienced.¹

Although palliative care is particularly important for people with advanced cancer, it is not just for people who are about to die. Control of symptoms is important at all stages of the disease, so may be required in early cases as well as in end-of-life situations.

Is medical treatment part of palliative care?

Medical treatment is an important part of palliative care. It aims to manage the physical and emotional symptoms of cancer without trying to cure the disease.⁵

Examples of palliative medical treatment include:¹⁸

- radiotherapy to reduce pain at primary (i.e. the lungs) or secondary (e.g. bone or brain) cancer sites
- chemotherapy to stop the cancer growing into other organs
- medication to relieve constipation, nausea or pain
- medication for depression, anxiety or insomnia.

Who is involved in palliative care?

Palliative care brings together many different services and people.

Some elements of palliative care require input from a specialist doctor or nurse. Other elements of supportive care can be provided by a:¹⁹

- GP
- Aboriginal and Torres Strait Islander hospital liaison officer
- Aboriginal and Torres Strait Islander Health Worker
- health and community care (HACC) worker
- spiritual healer
- family and community.

Where can a person receive palliative care?

Palliative care can be given at home, in a hospital or at a hospice. Patients can generally move between places if their needs change and can stay for a short or long time.¹⁹

Often the person and their family and friends can choose where to have palliative care, although it may depend on what services are available in the local area. If a patient is cared for at home, special services can help the patient and their family with medical support, nursing care and equipment hire.¹⁸

A hospice is a place more like a home than a hospital where patients can be cared for by trained staff.⁵

6.8 Clinical trials and research

Cancer clinical trials are carefully designed research studies that investigate a new test or treatment for cancer in people. Trials may look at whether a treatment is safe, its side effects or how well a treatment or procedure works. Some trials look at how well treatments control symptoms or whether they improve quality of life. There are different types of trials asking different questions (Table 6.3).²⁰

In cancer research, clinical trials can answer questions about how to:

- prevent cancer, for example using diet, exercise or drugs
- find genes that may cause a particular type of cancer
- find cancer at an early and treatable stage, for example using screening blood tests, scans or other special tests
- diagnose cancer, for example using blood tests, scans or new technologies
- treat cancer, for example using surgery, drugs, radiotherapy or different combinations
- control symptoms of cancer or its treatment, for example using drugs and ‘complementary’ therapies such as diet, vitamins, exercise, yoga, meditation, hypnotherapy or acupuncture.

For more information about clinical trials, see the Australian Cancer Trials website (www.australiancancertrials.gov.au), a consumer friendly website about clinical trials conducted in Australia.

Table 6.3 Types of clinical trials

Type of trial	Description
Treatment trials	Test new treatments and/or compare them with standard treatments.
Screening trials	Test the effectiveness of methods used to detect cancer.
Prevention trials	Test whether a particular intervention stops cancer from developing. They involve people who do not have cancer.
Quality of life studies	Test how cancer and its treatments affect patients. They are usually conducted alongside a treatment trial.



Chapter 7

Psychosocial issues and practical support

7

Chapter 7: Psychosocial issues and practical support



This chapter provides guidance on ways you can support a person with lung cancer, their partner, family and community through the lung cancer experience. Throughout this chapter there are some facts about cancer that may help you provide support and information.

7.1 What are psychosocial issues?

People with lung cancer may experience a number of emotional, physical and practical challenges throughout their cancer journey. Together these are called psychosocial issues. They can be interlinked – so physical issues can affect how a person feels about themselves.

Challenges may be related to concern for family and community, questions about the physical side effects of treatment, and practical concerns, such as travel and treatment costs. More specific emotional issues can range from concerns about treatment to periods of anxiety or depression.

7.2 Emotional issues

Lung cancer may change how a person feels, and how they relate to other people in their life. Feelings may change at different stages along the cancer pathway. Some of the common feelings are listed in Table 7.1.²¹ Be aware that many people will find it difficult to talk about their feelings.

Table 7.1 Emotions that a person may feel when diagnosed with lung cancer

Fear	It's frightening to hear that you have cancer. Most people cope better when they know what to expect so providing accurate information is very important.
Anger	Patients may feel angry with health professionals or even themselves if they think they may have contributed to the cancer or a delay in diagnosis. This may particularly be the case in those who have smoked.
Disbelief	Patients may have trouble accepting that they have cancer. It may take time to accept the diagnosis.
Sadness	It is natural for a person with cancer to feel sad. However, if they experience continual feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave them pleasure, it is important that they are referred to a doctor – they may be suffering from depression and require treatment (see box next page).
Guilt	It is common to look for a cause of cancer. While some people blame themselves, it is important that people understand that no-one deserves to get cancer.
Loneliness	It is natural for people diagnosed with cancer to feel that nobody understands what they're going through. Patients might feel lonely and isolated if their family and friends have trouble dealing with their cancer, or if they are too sick to work or socialise with others and enjoy their usual activities.
Loss of control	Being told you have cancer can be overwhelming and make people feel as though they are losing control of their life.
Distress	Many people, including carers and family members, experience high levels of emotional suffering as a direct result of a cancer diagnosis.

Depression

Depression is quite common among people with cancer¹

Signs of depression	Continued feelings of sadness. Trouble getting up in the morning. Loss of motivation to do things that previously gave them pleasure.
What can help?	Specialised care is needed for people experiencing depression or suicidal thoughts. This will usually involve counselling and sometimes medications such as anti-depressants.
What can you do?	Ask regularly about the person's emotional concerns. Listen to the person and encourage them to share their concerns and fears. Be aware of symptoms of depression such as irritability, social withdrawal, and increased difficulty coping in general. It is important to refer patients on to their doctor to diagnose and manage more severe emotional reactions.

A person's response to their lung cancer diagnosis may be affected by:

- their diagnosis experience:
 - was finding out the results from the tests difficult?
 - did the doctor explain the information well?
- their past experiences and lifestyle:
 - has a family member passed away from lung cancer before?
- their age, stage of life and social role:
 - do they have a young family who depend on them?
- the physical burden of their cancer:
 - do they have to travel away from home to receive treatment?
- their prognosis:
 - has their cancer been found early or late?



Shame and stigma

The association between lung cancer and smoking means that people may experience feelings of guilt, blame and shame regarding their diagnosis.¹³ Stigma is associated with having a negative impact on a person's physical and social health.²² Stigma can impact a person's health by increasing their levels of stress, reducing their willingness to tell others about how they are feeling, and feeling discriminated against by others.²³

In some Aboriginal and Torres Strait Islander communities, it is believed that cancer is a result of 'payback', such as having offended a relative who that part of the body represents. For many Aboriginal and Torres Strait Islander people, a diagnosis of lung cancer is seen as a death sentence.²⁴

All of these feelings can contribute to the burden of illness for patients and their families through:

- delays in visiting the doctor
- delays in starting treatment or rejecting treatment because of feelings that it is not worthwhile³
- refusal of treatment because of a feeling that cancer is a form of 'payback'
- stopping treatment early
- increased emotional issues due to feelings of guilt, blame and shame.³

What can help?

Managing feelings of shame and stigma may be difficult. The stigma associated with lung cancer could lead to difficulties for patients in participating in support groups.²² However, it is important to provide information and education that effective treatments are available and are improving over time.

Relationships and self-image

A diagnosis of cancer can affect how a person feels about themselves and how they relate to others. People with lung cancer may experience:

- changes in how they feel about their body after diagnosis and treatment for cancer; this could be because of scarring or body changes after surgery, disease symptoms, or side effects of treatment like weight changes and hair loss
- strain on relationships with people close to them, particularly their partner; a cancer diagnosis can be just as overwhelming and distressing for partners and other close family members as it is for the person diagnosed.

Who can help with emotional issues?

GPs: provide a link to a range of health professionals who can assist with emotional care and practical support services.

Nurses: experienced in helping people cope with physical symptoms and emotional issues; they can also provide advice about other health professionals who can provide more specific support.

Social workers: provide advice about finances and practical support; they can also provide counselling, which can include other members of the patient's family, if needed.

Psychologists: provide counselling and can offer specific therapies.

Psychiatrists: doctors who specialise in mental health and the way the brain functions; in addition to counselling, they can treat conditions such as depression and anxiety and prescribe medication, if necessary.

Counsellors: listen and provide therapy to work out exactly what issues the patient is facing and what they would like to do next.

Spiritual advisors: can listen and discuss matters of faith.

7.3 Physical issues

People with lung cancer may experience a range of physical symptoms and side effects of treatment. Some of the common issues and what can help are listed in Table 7.2.^{3, 21}



Who can help with physical issues?

Nurses: experienced in helping people cope with physical symptoms and emotional issues; they can also provide advice about other health professionals who can provide more specific support.

Occupational therapists: provide practical support to overcome physical problems or barriers at home or work.

Physiotherapists: provide physical support, massage and manipulation to help with mobility and reduce pain.

Speech therapists: help with speech, eating and swallowing difficulties.

Dieticians or nutritionists: help to overcome eating difficulties and maintain a healthy diet.

Palliative care services: provide specialised symptom and practical support to manage the particular issues faced by people with a disease that cannot be cured; this includes management of pain and other symptoms.

Table 7.2 Physical issues associated with lung cancer and its treatment

What is it?	What causes it?	What can help?
Fatigue		
Feeling exhausted and lacking energy for day-to-day activities. Differs from normal tiredness as it often does not go away with rest. Common side effect of chemotherapy and can last three to six months after treatment is over. Can be very distressing for patients and affect quality of life.	Can be caused by the physical and emotional impact of diagnosis and treatment. Contributing factors include immobility, sleep disorders and poor nutrition.	Exercise during and after treatment can help reduce fatigue. Because fatigue can be linked to depression, it may help to refer patients to a health professional to talk about available treatments.
Breathlessness³		
Shortness of breath. Reported as more common in older patients, men, and those experiencing pain and anxiety.	Related to the location and stage of the cancer. Often caused by fluid collecting between the lung and the chest wall (known as pleural effusion). Can be caused by infection, anaemia, and other underlying conditions (emphysema or chronic bronchitis).	Determining underlying causes of breathlessness helps to direct management strategies. Can be improved by treating the cancer itself or by draining excess fluid. May also be improved by cough suppressants, steroids and antibiotics. Education about breathlessness is also fundamental for the patient and their family/carers.

Pain³

Can be described in terms of soft-tissue pain, bone pain or pain due to nerve damage.

May be caused by symptoms of the cancer or by the side effects of treatment.

Vital to find out the underlying cause of pain in order to decide the best treatment.

Treatment may include opioids, relaxation therapy, massage, and educational programs aimed at enhancing pain control.

Radiotherapy is often helpful for some types of pain, such as that associated with bone tumours.

Severe pain that is difficult to control generally requires specific pain management from specialists.

Cough

Dry cough.

May be caused by radiation therapy to the lungs.

Symptoms are likely to improve once treatment is over.

Difficulty in swallowing

Difficulty in swallowing due to inflammation of the oesophagus.

Eating soft food or a liquid diet can be helpful.

Symptoms are likely to improve once treatment is over.

May be caused by radiation therapy to the lungs.

7.4 Practical issues

For anyone with cancer, there are many practical issues to think about. These may include the cost of treatment, support services, travel, accommodation or childcare. There are also ongoing finances to think about if there is no regular income for the patient. This can add to the stress and anxiety that the patient may already be feeling about having cancer and going through treatment.

Practical challenges can also have an impact on family and community. Sometimes people feel guilty that their cancer treatment means the rest of the family has to make changes to the way they are used to doing things. Concern about these practical issues can affect how the patient is feeling, especially if it interrupts their daily activities.

Remember, emotional care and social support is just as important as physical care during the cancer pathway

Understanding the health system

For Aboriginal and Torres Strait Islander people and their families, hospital visits and stays can be a daunting prospect, especially if this means being away from home. It can be helpful to describe what is likely to be involved during diagnosis and treatment for lung cancer, and the various health professionals involved. Preparing patients and their families for what to expect can help reduce fear and anxiety.

Special considerations for patients from rural and remote areas

It is important that patients from rural and remote communities who have to travel for treatment and support services have information about travel and accommodation and are given advice about available financial assistance.³

Assistance for patients who are required to travel for treatment

If a patient needs to have treatment in a hospital far away from home, they may be able to get help with the cost of accommodation and travel. Depending on the situation and where they live, they may also be able to get assistance with childcare, meals and general home help. Some people may also be eligible for a sickness allowance while having treatment.

Each State and Territory has a government-funded scheme to help patients who have to travel long distances to obtain specialist treatment that is not available locally. The names for these schemes vary but may include:

- Transport for Health – Australia-wide
- Patient-Assisted Transport Scheme (PATS) – South Australia
- Isolated Patient Transport and Accommodation Assistance Scheme (IPTAAS) – NSW
- Victorian Patient Transport Assistance Scheme (VPTAS) – VIC.



Many Aboriginal and Torres Strait Islander people have a strong sense of home, and value being at home or close to home, particularly when ill.³

Aboriginal and Torres Strait Islander people have strong links to the land and a sense of 'home'. This connection can be strong regardless of whether they are living a culturally-traditional lifestyle in remote locations, or in urban areas.

Some patients may be reluctant to leave their community for treatment, even though this care may only be available in a remote urban setting.

The financial cost of lung cancer

The cost of testing and treatment for lung cancer can differ from person to person. The costs may vary depending upon if the person:

- is treated in the public or private system
- lives in a rural area and needs to travel for treatment
- has private health insurance
- has a healthcare card

For people who are working, diagnosis and treatment for lung cancer can affect their ability to work for a short or longer period of time, and this can also affect their finances.

Superannuation for people with a terminal illness

Current legislation allows individuals with a terminal illness to access their superannuation as a tax-free lump sum. In order to do this the patient will need certificates from two medical practitioners (one of whom is a specialist) stating that they have a terminal illness with a life expectancy of 12 months or less.

Travelling with oxygen

Some people with lung cancer require oxygen to help with breathing. For patients who need to travel for treatment or tests, this means having a portable oxygen supply.

The following guidelines on travelling with oxygen have been provided by the Lung Foundation Australia:²⁵

There are two key considerations when travelling with oxygen:

- ensuring safe transport for their normal oxygen supply
- use of portable oxygen while in transit.

Transporting home concentrators

Home oxygen concentrators are transportable (although heavy), and can normally be taken away while travelling. It is important to talk to the supplier about how to transport it safely. Some general guidelines are provided below.

- Concentrators must be carried upright. They may be damaged if transported lying flat or on their side.

- If travelling by car, put the concentrator in the boot if possible, or on the back seat restrained by a seatbelt.
- Check with the airline or travel provider to make sure they will allow the concentrator on board as luggage, and ask about any extra costs. It may be cheaper and easier to hire one and have it delivered to where the patient is staying.

Transporting portable cylinders

- Ask the supplier for instructions on how to safely transport the oxygen cylinders.
- Check with the airline or travel provider to ensure they will allow cylinder/s on board as luggage.
- Alternatively, arrange to hire cylinders at the destination.

Using oxygen during the journey

Here are some questions that you or your patient should ask their travel provider:

1. Can the patient use their own portable oxygen cylinders during the journey? If not, what special arrangements can you make for the patient? How much will this cost?
 - Many airlines do not allow people to take their own portable oxygen cylinders on board for safety reasons. Instead the patient may need to hire an aircraft-approved oxygen cylinder or arrange in-flight oxygen through the airline. Remember that these arrangements can take time.
 - If the patient is using the airline's own in-flight oxygen equipment, they may not allow them to take it off the plane. So, if they have a stop-over on their journey, they will probably need to arrange a different oxygen supply for the time they spend on the ground in between flights. Direct routes, wherever possible, are easier for this reason.
2. Can the patient use their own portable concentrator during the journey?
 - Some portable oxygen concentrators are easy to use on board planes and other modes of transport, and can then be used during stop-overs as well. It is wise, however, to check that the company the patient is travelling with will allow the concentrator on board.

- The patient may need to book a seat near an appropriate power source so the concentrator batteries can continue to charge in transit. This is especially important for long journeys where the concentrator may need to operate for many hours.

Help with practical issues

Cancer care coordinators and specialist rural nurses: can be very helpful in providing a link between local services and the specialist doctors.

Palliative care services: provide specialised symptom and practical support to manage the particular issues faced by people with a disease that cannot be cured; a palliative care physician may need to approve the requirement for portable oxygen in some services.

Using teleconference and videoconference facilities: some hospitals allow some patient consultations to be conducted remotely, reducing the need for the patient and their families to travel.³

Social / welfare workers: can provide information about financial and practical support services available.

Local Medicare offices: can provide information about the ‘safety net’ on costs of medications and medical bills; can also contact the person’s private health insurer to discuss their likely rebates and benefits.

7.5 Providing support to Aboriginal and Torres Strait Islander people with lung cancer

Currently little is known about the preferences of Aboriginal and Torres Strait Islander people for support through cancer diagnosis, treatment and into survivorship or end-of-life care. However, we do know that there is a need for greater financial, social and psychological support.

Providing emotional and practical support to Aboriginal and Torres Strait Islander people with lung cancer is often considered to be the role of family members. However, in some cases family members may be unable to provide this support, particularly when a patient has to travel to receive treatment.

Some general examples of support are provided in the following chapter, but as an Aboriginal and Torres Strait Islander Health Worker you may need to tailor some of the options to reflect the cultural and spiritual needs of the individual patient.

You may encounter a number of barriers throughout this process. These may include:

- low expectations from Aboriginal and Torres Strait Islander people of the service they will receive due to a previous experience
- a lack of acknowledgement of their extended family during treatment in a hospital environment
- communication barriers and perceived poor communication with medical staff.

7.6 Sources of support available for people with lung cancer

It is important for people affected by lung cancer to have the opportunity to talk about the condition and how they are feeling. There are different forms of support that can help a person to get through the emotional, practical and physical challenges of a lung cancer diagnosis and treatment. Some examples are listed in Table 7.3.

Table 7.3 Sources of support for people with lung cancer

Peer support groups	Give patients the chance to meet and talk with people who have been through, or are going through, similar experiences. Often people say they feel less anxious and alone, and more optimistic about the future, after meeting with a support group.
One-on-one support	Could be useful for people who may not feel comfortable in a group situation and prefer one-on-one support from someone who has been through a similar experience.

Support programs	Provided in many hospitals or cancer centres, where the patient and their family can receive information about cancer and discuss how they are coping.
Family or couples therapy	Can be helpful to improve communication about how the different members of the family are feeling.
Psychological therapies or treatments	Usually provided by a psychologist or psychiatrist. Can help patients who are experiencing high levels of distress and anxiety to improve quality of life, reduce anxiety and depression, and help with physical symptoms. Include therapies to change unhelpful thoughts or behaviours, learn specific coping skills or relaxation techniques.
Exercise and education	May focus on breathing control and relaxation techniques, which can help to reduce nausea, vomiting and breathing difficulties.
Support centres	
Day centres	Often attached to hospitals, hospices or nursing homes and are available to provide support. Open during the day and often provide transport to and from the home. In some locations there are specific Aboriginal and Torres Strait Islander day centres or programs.
Hospitals	Public and private hospitals can provide short or long-term treatment. Access to a public hospital will depend on the level of need and whether there are beds available.
Hospices/palliative care units	Specialise in the care of people who are living with, and dying from, cancer (see Chapter 8). Focus on controlling pain and other symptoms. Some people go to hospices for a short period to help to control symptoms. Palliative care units may be wards in local hospitals.

7.7 Support for family and community

Being diagnosed with lung cancer can have a big impact on a person, but it can also have a significant impact on those close to them – such as their partner, children and extended family. As an Aboriginal and Torres Strait Islander Health Worker, you play a key role in giving family members the opportunity to discuss their feelings and experiences. You may also need to explain the support services available to family members affected by lung cancer, including how they can be accessed.

In some cases, a professional counsellor may be useful. Where possible, it is important for people to be able to talk to counsellors who have a rapport with, and commitment to, the community and who will respect confidentiality. Bear in mind that mainstream counselling services are generally not well equipped to meet the needs of Aboriginal and Torres Strait Islander clients.



Partners

Many partners find the diagnosis and treatment of lung cancer distressing, but are reluctant to seek help for themselves because they feel the need to be 'strong'. However, it has been shown that partners can experience higher levels of stress than the person actually diagnosed with cancer. As a result, they also have important support needs.

People with lung cancer should be encouraged to have open communication with their partner about how they are feeling. Partners can accompany patients to appointments to provide support and ask questions. Separate appointments can also be made for a patient's partner to discuss how they are feeling.

Children

Children are likely to be affected by their family member's diagnosis of cancer. Depending on their age, they may know that something is wrong without being told.

Helping families to have open and honest communication with their children, especially older children, is generally helpful. Here are some key points for families to keep in mind when communicating with children:

- try to understand what it is that the children fear will happen; this will help guide you in deciding what information they can handle and how it should be given
- talk to them about feelings as well as facts
- give simple, honest answers to their questions and correct any misunderstandings
- try to explain what will happen next
- reassure them that even if things are not good at the moment, there will be better times
- reassure them that lung cancer is not their fault – this is particularly important for young children.



Fast fact

It can be difficult for children to adjust, especially if their family member looks different or is in hospital. Children may reflect the effects of the diagnosis in their behaviour; they may behave differently to gain attention, or become insecure.

Young people may have mixed emotions, loyalties and coping abilities. In some respects, they thrive on being regarded as an adult, but during times of illness in the family, it can be hard going for them. As a result, young people may need additional support and encouragement.

Table 7.4 Tips for communicating with children about lung cancer

Things to do	Things not to do
Talking	Keeping secrets
Maintaining routine	Letting go of structure and rules
Negotiating tasks	Giving orders
Telling children it is not their fault	Telling children to be good for Mummy or Daddy
Encouraging children to participate in sport and normal activities	Expecting children to spend all of their time at home because time together is precious
Giving information in stages	Talking about possible outcomes far in the future
Allowing others to offer support	Thinking you can do it all on your own
Letting children talk about difficult things	Rushing to reassure
Encouraging children to work out problems themselves	Trying to fix everything for them
Letting the school know	Keeping everything private
Maintaining rules and consequences	Letting discipline slip because of guilt
Letting them see that you are upset sometimes	Always adopting a façade and pretending everything is okay

Helpful resources for parents and children

- Cancer Council NSW has developed a booklet “Talking to kids about Cancer” which can be downloaded at: www.cancercouncil.com.au
- Cancer Council NSW has developed a booklet “Cancer in the School Community” to assist staff members who would like to support children, students and parents with cancer. The booklet can be downloaded at www.cancercouncil.com.au
- CanTeen provides information and support for young people (aged 12–24) who have a family member with cancer: www.canteen.org.au

7.8 The role of the Aboriginal and Torres Strait Islander Health Worker

How you can help

As an Aboriginal and Torres Strait Islander Health Worker, you play a key role in giving people with lung cancer the opportunity to discuss their feelings and experiences. You will also need to explain the support services available to them, including how these can be accessed. When discussing support needs, it is important to consider:

- the importance of the physical, social, emotional, cultural and spiritual wellbeing of the individual and of the community and the environment as a whole
- the view of the body as the centre of social relationships, and the close link between health and family, community and other signifiers of identity
- the important link between being healthy and being able to fulfil a social role within the community.

Looking after yourself

The role of an Aboriginal and Torres Strait Islander Health Worker can sometimes be stressful and emotionally draining, particularly when providing care and support to family or friends or when working in palliative care.

It is important to look after your own health and seek support if needed. Talking to your manager about how you are feeling can be a good place to start. Many workplaces also have employee assistance programs that can offer professional counselling services. The following organisations can also provide support:

- Cancer Council Helpline: 13 11 20
- Lifeline: 13 11 44

Communication skills

Aboriginal and Torres Strait Islander people need accurate information about lung cancer and the relevant treatment options so they can understand their diagnosis and what lies ahead. Communication involves more than providing information – it includes explanation, problem solving and acknowledgment of the person's feelings.

The following skills may be useful when talking to people about their lung cancer experience.

Supportive communication

- explain how confidentiality is achieved between a patient and their healthcare professional
- ask the person if they would like someone (e.g. a family member) to be with them during any consultation with their doctors or specialists
- show care and concern for the person in the way you listen and respond to them. Remember to have open and attentive body language
- express empathy and listen actively
- allow and encourage the person to express their feelings, e.g. crying, talking about concerns, fears, anger, anxieties, etc
- handle embarrassing or disturbing topics directly and sensitively.

Delivering medical information in plain English

- assess the person's understanding before providing additional information
- explain difficult terms and avoid medical jargon
- provide information clearly and group it by specific topics.

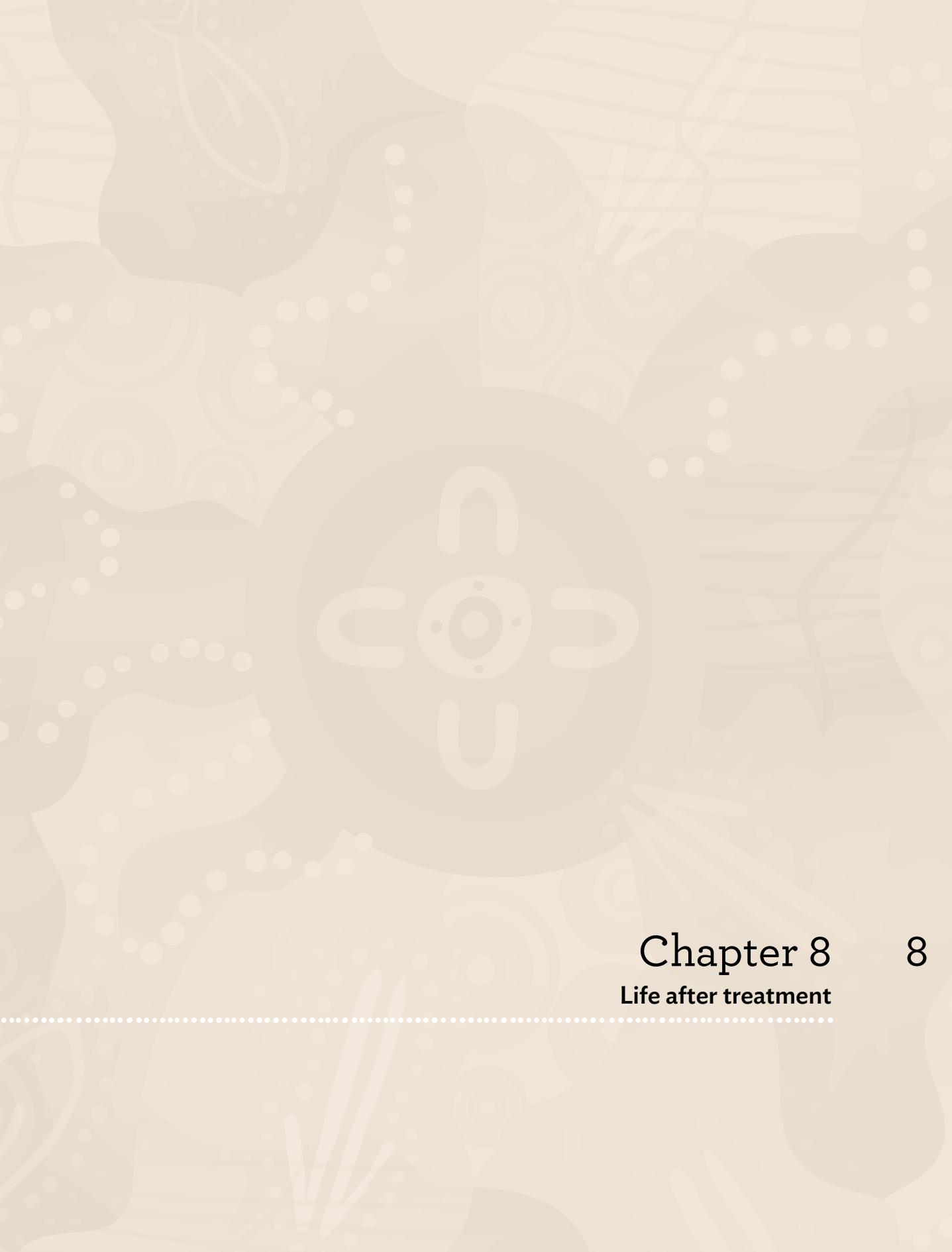
Help with understanding

- encourage the person to ask questions and seek understanding
- make use of simple diagrams and pictures, where appropriate
- repeat and summarise important information
- reinforce important information by using one or more of the following aids:
 - writing down relevant information
 - recording the consultation as needed and if wanted
 - sending a summary letter as follow-up.

PSYCHOSOCIAL ISSUES AND PRACTICAL SUPPORT

Some practical ideas for supporting Aboriginal and Torres Strait Islander people with lung cancer:

- generate a list of psychosocial support and practical services in your community
- start a support group for Aboriginal and Torres Strait Islander people with lung cancer or even all cancers. Groups can meet as regularly as they would like to, but generally once a week or once a month. You may want to organise guest speakers to present on different topics
- promote key messages to all Aboriginal and Torres Strait Islander people with lung cancer within your local community.



Chapter 8

Life after treatment

8

Chapter 8: Life after treatment



This chapter will assist increasing an understanding of what happens following lung cancer treatment. This includes information about finishing treatment, the importance of follow-up care, and cancer recurrence.

8.1 Finishing treatment

For people who have treatment with the intent of curing their cancer, the time will come when their treatment is over. Many people look forward to finishing hospital-based treatment (surgery, radiotherapy or chemotherapy). However, for some people, the end of treatment can be a confusing or worrying time. Some people feel nervous or upset at the thought of no longer seeing members of their healthcare team regularly. Others feel worried about what the future holds.

Patients may need support and reassurance at this time. Follow-up care is an important part of providing supportive care to patients after their treatment for lung cancer.

8.2 Follow-up care for patients treated for lung cancer

Follow-up care for people who have finished treatment for lung cancer is important to help:

- check that the cancer does not come back
- detect disease that has spread to other parts of the body (known as metastases)
- manage side effects of treatment
- monitor physical and psychosocial supportive needs.¹

There is no standard approach to follow-up care following treatment for lung cancer. The approach will vary according to the patient's individual needs and the aims of their initial treatment.⁵

It is important that after-care treatment for patients is well co-ordinated and integrated. A patient-centred after-care treatment approach should be agreed with the patient, carer and the nominated co-ordinator of care, for example the patient's doctor, medical oncologist or respiratory physician.

Typically, follow-up care will be more frequent in the first two years following treatment. It may become less frequent in later years.

If a patient starts to experience any symptoms of lung cancer between follow-up appointments, it is important that they do not wait until the next appointment to report them. They must see their doctor or specialist as soon as possible.

Follow-up tests are likely to be undertaken by one or more of the specialist doctors involved in diagnosing and treating the lung cancer and are likely to include physical assessment, checking of symptoms, imaging tests and discussion about physical and emotional wellbeing. The patient's doctor may also be involved in follow-up appointments.

Follow-up visits also provide an opportunity for health promotion and wellness discussions, including:

- smoking status assessment (with an offer of specific medication, counselling and referral for cessation, as needed)
- patient counselling on symptom recognition and reporting of symptoms if concerned
- review of immunisation schedules, such as annual flu vaccinations.

8.3 Advice for patients

Talking to the doctor

Follow-up appointments are a good opportunity for the patient to talk to their doctor about their feelings regarding lung cancer now that their treatment is over. It is also an opportunity for them to talk about any side effects of treatment they may have had since their last visit.

As an Aboriginal and Torres Strait Islander Health Worker it is important to stress the need for patients to tell their doctor about any side effects or symptoms they are experiencing.

Involving the family

For Aboriginal and Torres Strait Islander people family and kinship is central to wellbeing. It is important to be aware that family responsibilities may impact greatly on treatment decisions and that involving family in the decision-making process may increase the acceptability of treatment options, as well as completion of, and compliance with, treatments and follow-up care.

8.4 If the lung cancer comes back

Patients treated for lung cancer have an increased lifelong risk of the cancer returning which is why follow-up care is so important.³

Management of recurrent disease

Treatment usually focuses on controlling the disease and its symptoms. This includes a palliative approach to care (see Chapter 9). Treatment plans are decided in the same way as the initial treatment plan. This will require further testing to determine the extent of the lung cancer as well as discussion of patient preferences.³

Treatment will depend on the location and extent of the lung cancer, as well as consideration of the treatments used previously for that patient.

Cancer recurrence is the return of the cancer after a period of time in which no cancer could be detected. Recurrence is common in lung cancer, particularly in those with poor general health factors, such as poor nutrition and continued use of alcohol and tobacco.³

How patients might feel

If lung cancer comes back after treatment, this can be very challenging and upsetting for patients. It is likely that they will be more pessimistic about their future. Patients, their family and carers should be fully informed and counselled about the likely outcome of any further treatment, and should be helped to weigh up the balance of the benefits of treatment and side effects with the likely effect on their survival and quality of life.

8.5 Follow-up care for patients treated with palliative intent or who received no active treatment

The purpose of follow-up care after palliative treatment and/or no active treatment is to monitor disease progression and provide symptom control.³

Follow-up care at this stage should involve:³

- access to a specialist with an interest in lung cancer
- investigations agreed to by the designated lead specialist, doctor and patient
- access to allied health providers for symptom management, such as physiotherapy, occupational therapy and palliative care.

8.6 The role of the Aboriginal and Torres Strait Islander Health Worker

Little research has been conducted on follow-up care for cancer among Aboriginal and Torres Strait Islander people. However, we do know that the risk of dying for all cancers is higher compared with the non-Indigenous population.

Despite the little research available for the Aboriginal and Torres Strait Islander population, studies show the need to:

- prevent cancers, particularly those with a higher risk of death
- find cancers earlier
- promote the benefits of completing treatment and attending for follow-up care.

Structured and busy specialist clinical services may not cater well for the cultural needs of Aboriginal and Torres Strait Islander people. This can contribute to a broader sense of disillusionment, indifference and apathy – which may in turn reduce adherence to follow-up care.³

How you can help

A key role of the Aboriginal and Torres Strait Islander Health Worker is to support the patient to undertake long-term follow-up care. This means supporting them to attend appointments, continue to take any prescribed medications for as long as required, and to be aware of and report any symptoms of lung cancer or side effects of treatment drugs.

In addition, during contact with people in follow-up care for lung cancer, the following steps are recommended:

- ask the patient how they are feeling about their treatment
- listen to fears and concerns
- ask the patient about their support networks e.g. partner, children and extended family
- provide the patient and their family and carers with information about support services and peer support programs, and how they can be accessed
- coordinate and liaise with local health professionals and specialists who are providing follow-up care and may be in different locations.



Chapter 9 9

End-of-life care

Chapter 9: End-of-life care



This chapter provides guidance on ways to support a person with lung cancer, their family and the community towards the end of their life.

9.1 End-of-life care

The physical burden faced by patients at the end of life can have a major effect on their emotional wellbeing, and the emotional wellbeing of their family/carers. This may be exacerbated by spiritual issues arising from being confronted with their own mortality.³

As the patient nears end of life, the specialist palliative care team may become the primary specialist service involved in patient care, working alongside a GP and other primary care providers. Importantly, early referral to palliative care can provide a positive effect on quality of life and end-of-life care for patients with lung cancer.³

The transition to care primarily led by the specialist palliative care team is best done in a coordinated fashion between the specialist groups, so that the patient understands the reason for the transition and how it will occur. This should also help ensure that the patient and their family/carers continue to feel well supported.³

The place of dying and death has cultural and spiritual significance for many people from Aboriginal and Torres Strait Islander communities. The need to ‘return to country’ is very important for many Aboriginal and Torres Strait Islander people at the end of their lives.

9.2 Advanced care planning

While advanced care planning relates to care at the end of life, it should be discussed with patients following a cancer diagnosis and early in the course of their disease.³

Advanced care planning can provide the patient, their family and carers the opportunity to take control of decisions that affect their care, if at some point in the future they no longer have the capacity to make those decisions themselves. The patient will need to be an adult and have capacity to make an advanced care plan.²⁶

Advanced care planning allows people to make their preferences for important health care and personal decisions known, in the event that they lose their ability to make decisions for themselves.³

Advanced care planning may involve:³

- discussing prognosis and possible future scenarios
- appointing a substitute decision maker, and involving this person in on-going discussions
- deciding on current and future goals of care
- discussing patient choice for place of care
- documenting all discussions in an easy to access format.

Patients can make the advanced care directive as simple or as detailed as they like. If they have religious beliefs that may affect their health care decisions, they can record these in their advanced care directive.⁷

9.3 Getting affairs in order

When a person is diagnosed with advanced cancer, it can be useful to discuss with them the importance of getting their affairs in order. This includes organising personal, financial and legal affairs, collecting all relevant paperwork and making decisions, such as writing a will or agreeing on funeral arrangements. While this can be hard for the patient, it can also bring a sense of relief and allow the patient to focus on treatment and living.²⁶

Where appropriate, patients should be encouraged to talk to a lawyer or a financial planner about their specific legal and financial situation, as rules and regulations differ for each state and territory in Australia.²⁶

Organising paperwork²⁶

It is a good idea for the patient to have all of their paperwork in one place. This will make it easier if, for example, they need to be in hospital for a long time and a family member 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
- funeral information
- house title/lease documents
- will
- passport.

Encourage the patient to discuss their legal arrangements with their family, and tell someone close where they keep their legal documents or how to contact their lawyer.

9.4 The role of the Aboriginal and Torres Strait Islander Health Worker

Culturally based beliefs and values may play an increasingly significant role during end-of-life care for Aboriginal and Torres Strait Islander people.

What your patient may feel or experience at this time

- *Patients may feel distressed or confused at being separated from family through relocation for treatment.* Aboriginal and Torres Strait Islander people coping with serious illness strongly want to be cared for by family members. For this, and other reasons, Aboriginal and Torres Strait Islander people often do not want to relocate for respite or treatment during end-of-life care.²⁷
- In relation to kinship, people who may be regarded by Western culture as distant relatives may in Aboriginal and Torres Strait Islander cultures have strong responsibilities to the patient or their family. As a result, it will be important for patients to pay their last respects before death, even if this requires travelling long distances.²⁷

How you can help

Aboriginal and Torres Strait Islander Health Workers play an important role in palliative and end-of-life care. This may involve:

- providing appropriate community-based care and liaising with other health professionals involved in planning and delivering end-of-life services
- communicating clearly and developing trust with patients and their families and carers.

Providing culturally appropriate end-of-life care

As end of life approaches, all efforts should be made to allow patients to spend their remaining time in the place of their choice, whether this is in their home, hospital or inpatient hospice unit.

Health professionals should also be mindful of the possibility that this preference may change close to the end of life.³

Helping family and community during end-of-life care

There may be many people from the extensive family networks who come to see the patient at the end of their life.

In cases where the patient is being cared for away from home, distant relatives may be subjected to policies that restrict visitor numbers. This can be very distressing for extended family members.²⁷

It is important for health providers to foster cultural respect in institutions such as hospitals and hospices by supporting the needs of the extended family. This may include providing areas for large family meetings and, wherever possible, relaxing the visitor number policies.²⁷

Additional Information

Additional Information



In addition to the information provided by your health service or organisation you might find it helpful to get information from different sources.

Cancer Council helpline

Call the Cancer Council Helpline on 13 11 20 for up-to-date, local information that is relevant for you, and the person with lung cancer that you are supporting. If your patient is not able to access the internet, the Cancer Council Helpline may be able to print out information from relevant websites and mail these to the patient.

Useful links

‘Surfing’ the internet can be a useful way to find information. However, keep in mind that the information you find may not always be accurate. If you are accessing information to use with your patients, use careful judgment and always check what type of organisation has provided the information.

Your patients may also be accessing information on the internet, via a personal computer or at local libraries and in internet cafes.

Australian websites that may be helpful

Cancer Australia www.canceraustralia.gov.au

Cancer Australia is the national authority on cancer control, funded by the Australian Government. The Cancer Australia website provides evidence-based information about a range of cancers, including lung cancer. The website includes an Aboriginal and Torres Strait Islander specific page.

Australian Indigenous Health Info Net www.healthinfonet.ecu.edu.au

This is a website that is a ‘one-stop info-shop’ for people interested in information on health and wellbeing of Aboriginal and Torres Strait Islander people. There is information on cancer among Aboriginal and Torres Strait Islander peoples under the Chronic Conditions tab

CanSpeak www.canspeak.org.au

This is a national network of consumers and consumer organisations representing people affected by cancer (formerly Cancer Voices Australia)

Consumer Health Forum www.chf.org.au

This is a national organisation the provide leadership in representing the interests of Australian healthcare consumers

Cancer Council Australia www.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

CanTeen www.canteen.org.au

This website provides support services to young people aged 12–24 living with cancer, including young people who have an immediate family member with cancer. This website has links to upcoming support programs in each State and Territory

Lung Foundation Australia www.lungfoundation.com.au

This website provides information and support to patients, health professionals and the general public. The website provides links to information and support programs specific to each State and Territory

Other useful contacts

- **Centrelink** www.humanservices.gov.au
 - Disability, sickness and carers: 13 27 17
 - Provides information about government support and financial assistance.
- **Medicare** www.humanservices.gov.au
 - General enquiries: 13 20 11
 - Provides information about Medicare claims.
- **Department of Veterans Affairs** www.dva.gov.au
 - General enquiries: 13 32 54
 - Provides information about support and assistance available to Veterans.

Useful Resources

Our lungs our mob community education resource (2014)

Cancer Australia developed ‘Our Lungs Our Mob’ – community education resource for Aboriginal and Torres Strait Islander Health Workers and other health professionals to use to run lung cancer awareness workshops. The workshops aim to increase awareness of the symptoms and risk factors for lung cancer. The resource pack includes a facilitators guide and PowerPoint presentation to support the running of a community workshop and marketing resources. Free copies of the resource are available from Cancer Australia.

Let's yarn about lung cancer [DVD] (2009)

Lung Foundation Australia produced a DVD to educate the Aboriginal and Torres Strait Islander community on how to “look, listen and learn” about the risks and symptoms of lung cancer.

The DVD is available on the Lung Foundation Australia website:
www.lungfoundation.com.au

Archie Roach: Surviving lung cancer [DVD] (2014)

Respected Aboriginal singer/songwriter Archie Roach, shares his personal and moving account of the fears and challenges he overcame following a lung cancer diagnosis. Archie’s story is one of courage, determination and hope. Having survived lung cancer treatment, Archie says he “loves performing so much more”.

The DVD is available on the Lung Foundation Australia website:
www.lungfoundation.com.au

A cancer journey for remote Indigenous patients in the Northern Territory (2009)

This booklet has been produced by the Northern Territory Government Department of Health and Families with funding from CanNET. The booklet is an educational tool that details the cancer journey using plain language and images. The booklet begins with a description of cancer and goes on to discuss prevention, early detection, and testing. Different types of cancer are also discussed and information is provided on support, going to hospital, treatment, and follow-up care.

The booklet is accompanied by a DVD that contains information reflected in the book: www.cancerlearning.gov.au/docs/indig_can_journey.pdf

A cancer journey: a cancer story for remote Indigenous patients in the Northern Territory [DVD] (2009)

The Northern Territory Department of Health and Families program – CanNET – has put together a DVD explaining how cancer originates providing information on different types of cancer and its presence in remote Indigenous communities.

Both the booklet and DVD can be ordered from:

Acute Care Policy and Services Development
NT Department of Health and Families
PO Box 40596
Casuarina NT 0811
P: (08) 8999 2778

Aboriginal cancer journeys: our stories of kinship, hope and survival (2010)

A collaboration between Aboriginal Health & Medical Research Council (AHMRC) and Cancer Council New South Wales, the booklet contains different stories and experiences from Aboriginal people affected by cancer. Some stories are about the experience of being diagnosed with cancer, others are about the experience of caring for someone with cancer and some are about undertaking treatment.

The booklet also contains individual fact sheets included in a pocket in the back cover of the booklet. These fact sheets provide additional information about cancer, treatment and care options, as well as information to consider before undertaking any form of treatment.

The booklet can be ordered from:

Cancer Council New South Wales
153 Dowling Street
Woolloomooloo NSW 2011
P: (02) 9334 1900
F: (02) 9334 1741
E: feedback@nswcc.org.au

Glossary



During the investigation, diagnosis and treatment for lung cancer, patients will hear a lot of technical and medical terminology. This glossary provides a definition for some of these common terms.

Patients should be encouraged to ask their health professionals if they do not understand something their health professional has said.

A.

Adenocarcinoma	a cancer that starts in the glandular tissue of the lungs
Advanced cancer	cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured
Alternative therapies	treatments used instead of conventional treatments
Alveoli	the tiny air sacs in the lungs, where oxygen enters the blood and carbon dioxide leaves it
Anaemia	a condition in which there are fewer than normal red blood cells in the blood
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 for a period of time
Anti-emetic	a drug used to control nausea and vomiting
Asbestos	a naturally occurring mineral that forms long, crystallised fibres. Formerly used in manufacturing and building, asbestos use is now banned in Australia because its fibres can cause serious illness

B.

Benign	not cancerous or malignant. Benign lumps are not able to spread to other parts of the body
Biopsy	the removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease
Bronchiole	a small passage that carries air into the outer parts of the lungs
Bronchoscopy	a diagnostic test to examine the lungs and respiratory system
Bronchus/bronchi	tubes in the respiratory system that carry air into the lungs

C.

Catheter	a hollow, flexible tube through which fluids can be passed into the body or drained from it
Cells	the basic organisational unit of all living things. A human is made of billions of cells, which are adapted for different functions
Chemotherapy	the use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth
Clinical trials	studies that compare new treatments with standard treatments
Complementary therapies	treatments or therapies that can be used alongside conventional therapies
CT scan	a computerised tomography scan. This type of scan uses x-rays to create a picture of the body

D.

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

GLOSSARY

Ethics committee	a group of experts who review clinical trial protocols to make sure that the rights of the patients involved are protected
Emphysema	a non-cancerous condition in which the alveoli of the lungs are enlarged and damaged. It reduces the lung's surface area, causing breathing difficulties
F.	
Fine-needle aspiration	a biopsy procedure in which a fine needle is inserted into a lump to extract cells
H.	
Hand-foot syndrome	redness, tenderness, and peeling of the skin on the palms of the hands and soles of the feet, caused by certain chemotherapy drugs
I.	
Intravenous (IV)	inserted into a vein
L.	
Lobe	section of an organ. For example, the left lung has two lobes and the right lung has three lobes
Lobectomy	a surgical operation to remove a lobe of a lung
Lungs	the two spongy organs in the chest cavity, made up of large numbers of tiny air sacs. The lungs are used for respiration (breathing)
Lymph nodes	small, bean-shaped structures that form part of the lymphatic system. Also called lymph glands
Lymphatic system	a network of tissues, capillaries, vessels, ducts and nodes that remove excess fluid from tissues, absorb fatty acids, transport fat and produce immune cells
M.	
Malignant cancer	Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated

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

Multidisciplinary care a team approach to cancer treatment and planning

N.

Non-small cell lung cancer one of the two main groups of lung cancers. Includes squamous cell carcinoma, adenocarcinoma and large cell carcinoma

O.

Oesophagus the tube that carries food from the throat into the stomach

Oesophagitis temporary difficulty and pain in swallowing as a result of a long course of radiotherapy (i.e. several weeks)

Oncologist a doctor who specialises in the study and treatment of cancer

P.

Palliative care the holistic care of people with life-limiting illness, their families and carers. It aims to improve quality of life by addressing physical, emotional, spiritual, social and practical needs. 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 specialised imaging test that uses a radioactive glucose solution to identify cancer cells in the body

GLOSSARY

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 Healthcare Agreement
Pleura	membranes that line the chest wall and cover the lungs
Pleural cavity	the space that lies between the two layers of the pleura (lungs) and normally contains a thin film of fluid
Pleural effusion	an abnormal build-up of fluid in the pleural cavity (lung area)
Pneumonitis	a side effect of radiotherapy in which the lung becomes inflamed
Pneumectomy	a surgical operation to remove a lung
Primary cancer	the original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form
Prognosis	the likely outcome of a person's disease
R.	
Radiology	tests that involve taking pictures of different parts of the body
Radiotherapy	the use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply
Resection	surgical removal of a portion of any part of the body
Respiratory system	the system of the body responsible for breathing
Risk factors	things that increase your chance of developing lung cancer
S.	
Small cell lung cancer	a type of lung cancer strongly associated with cigarette smoking. It spreads early and causes few initial symptoms

Sputum	liquid coughed up from the lungs. Also known as phlegm
Sputum cytology test	examination of sputum under a microscope to look for cancer cells
Squamous cell carcinoma (SCC)	a cancer that arises in the squamous or skin-like cells of the body.
Staging	performing tests to determine how far cancer has spread
Steroids	drugs used to relieve swelling and inflammation
Systemic treatment	drugs such as chemotherapy or hormonal therapy that treat the whole body to destroy cancer cells

T.

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 new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant

U.

Ultrasound	a way of producing a picture of the inside of the body using sound waves
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W.

White blood cells	blood cells produced by the bone marrow that help the body to fight infections
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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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