About this guide

Being told you have lung cancer or could have lung cancer can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

Information and support

Cancer Council: For information and support, call Cancer Council on 13 11 20 to talk to an experienced healthcare professional or visit www.cancer.org.au.

For more information about lung cancer, look for Cancer Council’s Understanding Lung Cancer booklet on your local Cancer Council website.


Translating and Interpreting Service (TIS): If you need a translator, call TIS on 13 14 50 or visit www.tisnational.gov.au.

Initial tests and referral

Symptoms

Wheezing, airway blockage or coughing up blood require immediate attention from an emergency department.

Other symptoms may include a new or changed cough, chest/shoulder pain, a persistent chest infection, finding it hard to breathe or a change in your voice. If these last more than three weeks go to your general practitioner (GP).

Initial tests you may have

Chest x-ray. An x-ray takes a picture to see if there is anything wrong with your lungs.

Chest computed tomography (CT) scan. Computers and x-rays are used to make a detailed picture of the lungs.

Referrals

If your GP has concerns, you will be referred to a lung cancer specialist at a public hospital or in private practice for more tests. Lung cancer specialists are doctors who are highly trained in lung cancer.

You can bring a family member or friend with you to your appointments.

Timeframes

Your specialist appointment should happen within two weeks of referral.

If you can’t get an appointment within this time, follow up with your GP.

Questions you might want to ask

• Should I go straight to an emergency department?
• Can I choose whether I go to a public hospital or private practice?
• Can I choose the specialist I see?
• How much will appointments cost me?
### Diagnosis and staging

The specialist will do more tests to see if you have lung cancer. This process of working out if you have a medical problem is called making a diagnosis. You might have one test or a mix of tests:

- **Position emission tomography (PET) scan.** A small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.
- **CT scan** of the chest and upper tummy and sometimes of the brain.
- **Biopsy.** A small sample of your lung is taken to check under a microscope. This is sometimes guided by a CT scan or ultrasound.
- **Bronchoscopy.** A tube is used to look inside your lungs and take samples. This is done under a general anaesthetic (you will be put to sleep).
- **Endobronchial ultrasound.** A type of bronchoscopy where soundwaves are used to make a picture of the lungs.
- **Sputum cytology.** A sample of your phlegm (a type of mucus made in your chest) is collected and viewed under a microscope.

These tests will give the specialist more information about the cancer such as where exactly it is in your body, if the cancer is growing or if it has spread and what stage the cancer is. This is called staging. Staging helps to work out the best treatment for you.

#### Timeframes

- Results should be available **within two weeks** from when you have the tests.

#### Questions you might want to ask

- What is lung cancer?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What stage is my cancer?
- What support services are available to me?

### Treatment

There are several ways to treat lung cancer. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

- **Surgery** is where the cancer is cut out. It is the most common treatment for people with early-stage non-small cell lung cancer.
- **Radiation therapy** uses x-rays to kill cancer cells and stop the cancer growing. It is used if surgery is not a good option. Radiation therapy might be used alone, or with chemotherapy.
- **Local ablative therapy** uses radio waves to heat and kill cancer instead of cutting it out of your body. It is used if surgery is not a good option. Local ablative therapy might be used alone, or with chemotherapy.
- **Chemotherapy or drug therapy** uses drugs to kill cancer cells and stop the cancer growing. It might be used if surgery is not a good option. Chemotherapy might be used alone, or with radiation therapy.


Supportive care (treatment or services that support you through a cancer experience) are also available.

#### Timeframes

- Treatment should start **within six weeks** of your referral to a specialist.

You can ask your GP for a referral to another specialist for a second opinion.
Clinical trials
You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit www.australiancancertrials.gov.au.

Complementary therapies
Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.

If you smoke
Stopping smoking is one of the most important things you can do to improve your health and wellbeing. Stopping smoking can improve how well the treatment works, reduce the risk of complications during surgery and improve recovery after surgery. For individual and confidential support to stop smoking call Quitline on 13 7848, speak to your GP or specialist and visit www.quit.org.au.

Questions you might want to ask
- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?

Recovery
Cancer treatment can cause physical and emotional changes.

Follow-up care plan
Your healthcare team will work with you to make a plan for you and your GP. This plan will explain:
- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- understanding and dealing with side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Many people worry that the cancer will return. Your specialist and healthcare team will talk with you about your needs and can refer you to other healthcare professionals and community support services.
Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit www.cancercareguides.org.au

Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

Living with advanced cancer

If cancer returns

Sometimes cancer can return after treatment. It can come back in the same place or can appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how far the cancer has spread, how fast-growing it might be and the symptoms you are experiencing.

Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit www.advancecareplanning.org.au.

Palliative care

Your specialist may refer you to palliative care services, but this doesn’t always mean end-of-life care. Today people can be referred to these services much earlier if they’re living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Speak to your GP or specialist or visit www.palliativecare.org.au.

Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer. For more information visit www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment.

Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?