

Getting the best advice and care

A guide for those affected by lung cancer

If you have been diagnosed with lung cancer, it is natural to have many questions about how you will be cared for and what to expect as your care is planned and delivered. You will have many appointments, different tests, investigations and treatments, which may be at different locations or health services.

Cancer Australia has developed a Lung Cancer Framework to highlight key principles that are important to ensure best practice care is provided to people with lung cancer. This guide explains what you can expect when care is delivered according to the principles and contains advice on actions you can take to help you receive best practice lung cancer care.

Patient-centred care



Timely access to evidence-based pathways of care



Multidisciplinary care



Coordination, communication and continuity of care



Data-driven improvements in lung cancer care



Starting the conversation

Talking to the health professionals who are managing your treatment and care is the best way to make sure you get the care that's right for you. The **Starting the conversation** boxes give tips on ways to ask questions and discuss your concerns.

Each of these principles are important at different stages of the lung cancer pathway. The relevance of each principle to your care may change over time depending on your individual care needs and circumstances.

More information

Links to websites and resources that might be useful for you are listed throughout this summary. There's also a list of definitions and further information on the back page.

Patient-centred care

You, and your loved ones and carers, are the focus of your lung cancer care



What this principle means for you

- ▶ Your care and treatment take into account your individual needs, circumstances, preferences and beliefs.
- ▶ You receive relevant, evidence-based information to help you make decisions about your care.
- ▶ You and your loved ones feel supported, informed and respected throughout your lung cancer care.

Starting the conversation

"I'm a bit worried about..."

"Will I still be able to...?"

"Can you recommend a website / support group / information that might be helpful for me?"

"I have a list of questions – can I go through them with you?"

What you can do

- ▶ Ask your doctors for information that may be helpful for you and your loved ones, for example, patient resources about lung cancer or a list of proposed treatments.
- ▶ Bring a family member or friend to appointments so they can support you, listen, take notes and help you remember what your doctors say.
- ▶ Tell your doctors how you are feeling and what is important for you in your treatment and care.

Useful resources

Information about lung cancer
Cancer Australia

Understanding Lung Cancer
Cancer Council Australia

Better Living with Lung Cancer
Lung Foundation Australia

Question prompt lists for people with cancer
Cancer Institute NSW

Timely access to evidence-based pathways of care

Pathways are in place to support timely diagnosis, staging, treatment and care



Starting the conversation

"When is my next appointment and where will that be?"

"Who can I contact if I have questions?"

"What research can I take part in?"

What this principle means for you

- ▶ Your GP investigates your symptoms and refers you to a specialist lung cancer multidisciplinary team for diagnosis and treatment.
- ▶ You have access to all critical tests, treatment and care for lung cancer in line with best practice guidance. This includes support and treatment to improve your quality of life.
- ▶ Throughout your care, the referral process and access to treatment is timely and smooth.
- ▶ Your doctors talk to you about research, including clinical trials, that you may be able to take part in.

Useful resources

Optimal care pathway for people with lung cancer State of Victoria, Department of Health and Human Services

Australian Cancer Trials website
Cancer Australia

Your pathway through lung cancer care Lung Foundation Australia

What you can do

- ▶ Ask your doctors about what to expect, including next steps, and where and when you will have tests and treatments.
- ▶ If it's hard for you to travel to appointments, ask your doctor about travel assistance or other ways of attending appointments (e.g. telephone or video appointments).
- ▶ Talk to your doctor about whether there are any suitable clinical trials you could join.

Multidisciplinary care

All your health professionals work together to coordinate your care



What this principle means for you

- ▶ Your treatment and care is managed by a team of lung cancer health professionals – called a multidisciplinary team (MDT). Team members may not all be at the same health service or location.
- ▶ Your multidisciplinary team meets to discuss a recommended treatment plan for you.
- ▶ A member of your multidisciplinary team, usually one of your doctors, talks to you about your treatment options and recommendations, and helps you decide on your individual treatment plan.
- ▶ Your individual treatment plan is written down and communicated to you and all members of your multidisciplinary team, including your GP.

What you can do

- ▶ Talk to your doctors about your options so your treatment plan takes into account what is important to you.
- ▶ If you don't understand your treatment plan, ask a member of the team to explain it to you.
- ▶ Tell the health professionals managing your care how you are feeling, and let them know of any concerns or preferences that might affect the treatment you receive.

Starting the conversation

"Who is on my multidisciplinary team?"

"Who on my team can provide support for how I am feeling?"

"I didn't understand what you said about... Can you explain that again?"

"Which doctor will talk to me about my treatment options?"

Useful resources

The treatment team

Cancer Australia

Lung Cancer MDT Directory

Lung Foundation Australia

Coordination, communication and continuity of care

All your health professionals work together to coordinate your care



Starting the conversation

"Who should I contact for advice about...or help with...?"

"Can any of my appointments be scheduled on the same day?"

"Can any of my appointments take place over the phone?"

"It would really help me if I could find out..."

What this principle means for you

- ▶ You have a lung cancer care plan that summarises your treatment and care.
- ▶ You know who to contact if you need advice or help.
- ▶ You and your loved ones feel informed about what is happening and what to expect.
- ▶ Your lung cancer team works together to coordinate your appointments and care, even if team members are in different services and locations.

Useful resources

Questions you may wish to ask about the time after treatment

Australian Cancer Survivorship Centre

Asking questions can help: An aid for people seeing the palliative care team

Palliative Care Australia

What you can do

- ▶ Ask who to contact if you have questions or need advice between appointments.
- ▶ Take someone to your appointments who can listen, take notes and help you remember what your team members say.
- ▶ Ask any questions – even if they seem small or if you've asked before but need further information.

Data-driven improvements in lung cancer care

Relevant data and information are used to improve the delivery of your care



What this principle means for you

- ▶ Your lung cancer team may talk to you about the types of information they collect and study that helps them improve the care they are delivering.
- ▶ Your lung cancer team may ask you for feedback about your care.
- ▶ The information you give (including your feedback) is used to improve cancer care and quality of life for you and other people with lung cancer.

What you can do

- ▶ Ask your team about the information they collect, how they collect it, and what it means for you. Some information may be collected as part of research study that you agree to take part in.
- ▶ Give feedback about your experience of services and your care. This is helpful for team members to know during and after your treatment and care.

Starting the conversation

“One of the things I am finding difficult each visit to hospital is...”

“I wish someone would have told me about...”

“What information do you have from other patients like me that might help me make decisions about my care?”

Useful resources

Consumer Learning: Consumer Involvement in Cancer Cooperative Trials Groups
Cancer Australia

Consumer Involvement in Research Program: Guide for Consumer Representatives
Cancer Voices Australia

Finding help and support

Cancer Australia – Cancer Australia is the national cancer control agency, funded by the Australian Government. Cancer Australia’s website provides evidence-based information about lung cancer and links to organisations providing help and support to people with cancer and their families. For more information, visit canceraustralia.gov.au

Cancer Council Australia – The Cancer Council in your state or territory can provide you with support and information on a range of cancer-related topics – call **13 11 20** from 9am to 5pm, Monday to Friday.

Cancer Voices Australia – Cancer Voices Australia is a national consumer advocacy organisation representing Australians affected by cancer. It aims to ensure the voices of people, their carers and families affected by cancer are heard at a national level.

Lung Foundation Australia – Lung Foundation Australia is a national charity dedicated to supporting anyone with a lung disease. They have a lung cancer network for lung cancer patients, their families and carers, and a lung cancer support nurse who can provide confidential support and information – call 1800 654 301 – Tuesday to Thursday.

Aboriginal and Torres Strait Islander people – Cancer Australia has developed *My lung cancer pathway: A guide for Aboriginal and Torres Strait Islander people and their families*, *Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer* and *Cancer - what to expect: Information for Aboriginal and Torres Strait Islander people who have cancer*.

Other languages — Cancer Australia provides information about cancer in 10 languages other than English.

Definitions

Care plan	A summary of the tests, treatments and other care you will receive. Your care plan is based on your individual situation and will take account of health conditions you may have in addition to lung cancer
Clinical trial	Research conducted with a patient’s permission to test different types of treatment or diagnostic tests
Lung cancer pathway	A summary that outlines the recommended steps in the care of someone with lung cancer. This includes recommended timeframes for tests and treatments
Lung cancer team	A multidisciplinary team of health professionals involved in the diagnosis, treatment and care of people with lung cancer. It may include doctors, nurses and allied health professionals together with your GP
Treatment plan	A summary of the lung cancer treatment(s) recommended for a patient.

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