

Living well with lung cancer: A carer's guide

If you are caring for someone diagnosed with lung cancer, it is important that you help them to look after their whole self – not just their lungs. As their carer, you can help them live well with lung cancer by taking a holistic approach to their life including their medical care, lifestyle, emotional wellbeing and planning for the future.



Medical care

For someone living with lung cancer, medical care becomes a part of their, and your, everyday life. Here are some things you can do to help make it as easy as possible on them.

1 Help them follow their treatment plan

Following the agreed treatment plan is essential for the person you are caring for as it can help control the cancer as well as any symptoms they experience. That's why it is so important they work together with their healthcare team to:

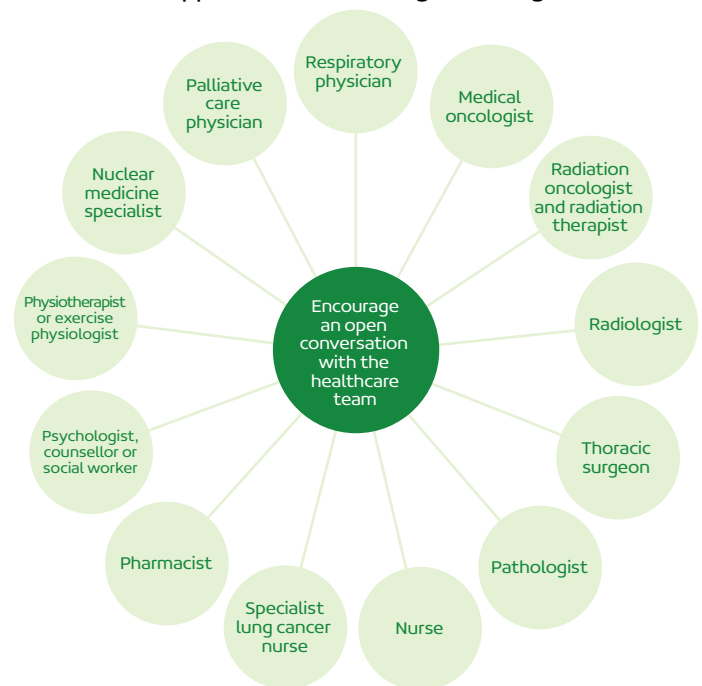
- Follow their prescribed treatment plan, which may include surgery, radiation therapy, anticancer drug treatments such as chemotherapy, targeted therapy or immunotherapy, or participation in a clinical trial
- Attend regular follow-up appointments to monitor their progress and manage any side effects

2 Ensure they have an open conversation with their healthcare team

People living with lung cancer have an entire multidisciplinary team dedicated to helping them live well with lung cancer. You can help make sure they get the most out of their team's expertise by supporting them to have open and frank conversations with all of the team.

- Encourage them to keep a list of questions or concerns that can be discussed with their healthcare team. You both might feel overwhelmed during some appointments, so keeping a list of queries can help make sure neither of you forget any
- If you or the person you are caring for are unsure about anything, from the treatment itself to any side effects experienced, make sure you ask about it. The healthcare team are there to offer support in any way they can
- Don't forget about their GP. GPs are an important member of the healthcare team for someone living with lung cancer. They can help coordinate medical care across all healthcare professionals, for example, by creating a GP Management Plan, or a Mental Health Treatment Plan which provides access to up to 10 individual sessions of mental-health treatment each calendar year

This diagram shows the team of health professionals available to support someone living with lung cancer.



3 Discuss a survivorship care plan with them

A survivorship care plan is an important document that can help manage the health of the person you care for after they have been diagnosed with lung cancer. It includes a personalised overview of their diagnosis, treatment, follow-up care, side effects to monitor for and actions they can take to promote their health. They should take the care plan with them to any future doctors or healthcare providers they see as it will help communicate their lung cancer diagnosis, the treatments they have undergone and the most-effective ways to monitor their health. They should also try and involve their GP in putting the plan together.

If you think this may help the person you are caring for, speak to their healthcare team and they can help develop a plan tailored to them.



Lung Foundation Australia's
Survivorship care plan



Lifestyle changes

Living with lung cancer may mean that the person you are caring for needs to make some changes to ensure they live their best life possible. Lifestyle changes can be hard, so make sure you remember that everyone is different – something that works for one person may not work for another.

1 Look after their lungs

Lungs are precious and fragile, so the person you are caring for should try and make sure they don't put their lungs under any additional stress:

- If they smoke or vape, encourage them to speak to their doctor to get help quitting. It's never too late to quit smoking or vaping
 - Recommend they call Quitline on 13 78 48. It's a confidential information and counselling service that can help people who smoke to quit
- Avoid exposure to second-hand smoke
- Stay indoors if the outside air quality is poor and try and avoid pollutants like car exhaust

2 Help them stay physically active

Exercise can help improve physical strength and fitness as well as fatigue, shortness of breath and overall quality of life.

- Work together with the person you are caring for to help incorporate regular exercise into their everyday life
 - Make sure they speak with their healthcare team before starting any new exercise regimen
 - If exercise is difficult for the person you are caring for because of side effects from treatment or the cancer itself, they should discuss it with their healthcare team. They may be able to suggest different exercises or treatments to help make physical activity possible
- The healthcare team may suggest pulmonary rehabilitation as part of their exercise plan. Pulmonary rehabilitation is an evidence-based exercise and education program that teaches and explains exercises that are suitable for someone living with lung cancer
- If the person you are caring for has lost muscle mass during or after their lung cancer treatment, an exercise physiologist can help them recover it. They can get a referral from their GP or oncologist



Discover more about exercising with a lung condition

3 Maintain a healthy diet

Eating well is always important, but even more so for someone trying to live well with lung cancer.

- Help make sure they eat a balanced diet by incorporating fruit, vegetables and legumes, wholegrains, meat (or alternatives) and dairy (or alternatives) while limiting foods that have saturated fat or added salt or sugar. If

the person you are caring for is not sure how to strike the right balance, they can speak with their healthcare team

- If the person you are caring for is currently undergoing treatment, there may be some foods they should avoid, so make sure they speak with their team
- Ensure they stay hydrated by drinking lots of water. If they don't like drinking water, consider trying diluted juice, herbal teas, coconut water or flavoured water
- Consider putting the person you are caring for in touch with a dietician to get personalised advice



Find a local dietician and read diet and nutrition advice

4 Be sun smart

Using sun protection like sunscreen, hats and adequate clothing can help reduce the risk of skin cancer, which is important for the person you care for to continue living well.

- Check their skin for any changes and schedule regular full skin checks



Emotional wellbeing

Emotional wellbeing is just as important as physical health for the person you are caring for.

1 Make sure they prioritise their mental health

It's normal for someone living with lung cancer to experience a range of emotions including fear, anger and sadness.

- You can talk to their healthcare team or their GP about how they can prioritise their mental health
- Encourage them to share their feelings with you and other family and friends so people understand what they are going through
- Suggest that the person you care for connects with other people living with cancer to exchange experiences and support each other

2 Help them to manage their stress levels

Going through treatment for cancer and wondering what comes next can cause anxiety and stress. You may be able to help the person you are caring for manage and reduce their stress by:

- Suggesting they try a relaxation technique that works for them such as adjusted deep breathing, meditation or yoga
- Encourage them to do things like hobbies or activities that bring them joy and relaxation like gardening, trips out of the house or crafts
- Recommend positive therapy or laughter yoga. They have been shown to improve wellbeing
- Their healthcare team may also offer classes such as art therapy or music therapy that they can take part in



Planning for the future

Part of living well with lung cancer includes being prepared for what is to come. The person you are caring for will talk to their healthcare team about what the future may hold based on their lung cancer diagnosis, but they also need to consider what they want for the rest of their life, regardless of how long that is.

1 Talk to their family and friends

Encourage them to discuss what is important to them and what they want to do and achieve in the future.

- They should also speak with their healthcare team so they can confirm what is possible and help the person you are caring for achieve their goals

2 Be screened for other cancers

People who have previously had cancer are often at higher risk of developing another primary cancer, so it is important that the person you care for participates in the National Screening Programs for bowel cancer, breast cancer and cervical cancer.

3 Help them organise their finances

Living with lung cancer can impact a person financially, so it is important that the person you care for understands and manages the costs now and for the future.

- The Cancer Council provides a free referral service to help people affected by cancer access free legal, workplace and financial assistance



Cancer Council: Legal, workplace and financial planning referral services

- If the person you care for is a mum living with lung cancer, Mummy's Wish offers practical and financial support for them and their family



Mummy's Wish

4 Determine the type of care they want towards the end of their life

This should include understanding how and where they want to die and if they want to be resuscitated or not. This will help ensure that you as well as their healthcare team and friends and family can make decisions in line with their wishes when the time comes. They might want to consider formalising their wishes legally. They can:

- Develop an advance care directive, which outlines their preferences for their future care along with their beliefs, values and goals

- Create a power of attorney, which gives someone they trust permission to make decisions about their care when they are not able to
- Make a will that outlines who should receive their possessions and property after their death. It can also include instructions on their funeral and burial arrangements



This blog may help you and the person you care for with some of these decisions

Connect with Lung Foundation Australia

Lung Foundation Australia are here to support you and the person you care for to live well with lung cancer.

1 Lung Cancer Specialist Nurse

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

2 Respiratory Care Nurse

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

3 Peer-support programs and groups

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

4 Lung Foundation Australia website

A comprehensive website with resources on lung cancer, a service directory to help find support and guidance that is right for the person you care for and the Mind Matters Hub which provides free information and resources about mental health and wellbeing.

For more information and to access support services from Lung Foundation Australia

- Visit: lungfoundation.com.au
- Free call: 1800 654 301
- Email: enquiries@lungfoundation.com.au

Caring for someone who is living with lung cancer can be challenging for you and the person you care for. But with the right plan and some support, you can help them maintain a good quality of life. And always remember that neither of you are alone on this journey.