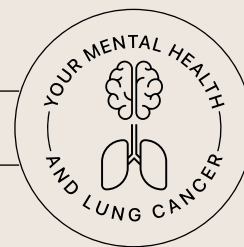




Lung cancer and your mental health

A guide to talking about and managing the impact of lung cancer on your mental health





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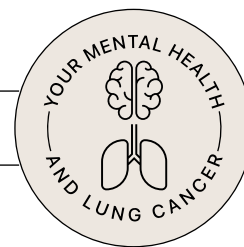
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01 Introduction

This guide aims to make one aspect of your lung cancer diagnosis a little bit easier – talking about and managing its effect on your mental health.

When producing this guide, we referred to many sources of information, which are listed under 'References' on page 17. The numbers in brackets throughout the guide show which of the sources the information came from.

The words that appear in blue throughout the guide are included in the glossary in Chapter 5.

A diagnosis of lung cancer can raise strong, yet valid, feelings in you and those close to you, such as **grief** for the loss of the vision you had for your life or **anger** at yourself, the world and your faith. This is normal and is part of coming to terms with your diagnosis. One thing to know is you are not to blame for your cancer, and you deserve help and support in dealing with it.

In this guide, we try to help you access that support, so you can deal with the shock of your diagnosis. We'll give you some ideas for ways you can support yourself through this difficult time and help you talk about how you are feeling so that others can support you. It isn't always easy to talk about feelings, especially when you are adapting to so many changes and are unwell. However, doing so can make a huge difference to your ability to cope, giving you access to support or treatment that can help. It can also provide peace and comfort for the family.

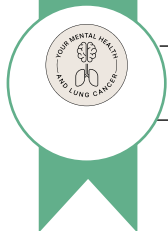
Evidence shows mental health support and treatment improve the quality of life in people with lung cancer. In those with **clinical depression**, treatment has also been shown to reduce symptoms such as tiredness and pain.^{1,2} Meanwhile, undetected or untreated depression has been linked to worse immune responses and poorer survival in people with cancer, so getting the help you need is incredibly important.^{3,4}

We hope this guide makes having these conversations easier, so you can access support, feel better and live the best life you can with cancer.

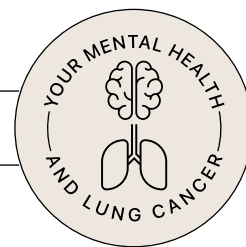
YOUR FEELINGS ARE NORMAL



CHAPTER 02



YOUR FEELINGS ARE NORMAL



Your feelings are normal

Feelings about your diagnosis

Many people with lung cancer struggle with the effect of their diagnosis on their mental health.^{5,6,7} These negative feelings are often referred to as **psychological distress**. Unfortunately, there is still **stigma** surrounding lung cancer and this is one reason why psychological distress is more common than for other types of cancer.^{5,6} Evidence shows that around 60% of people with a lung cancer diagnosis will experience psychological distress.⁷ Remember, you are not to blame for your illness and deserve the best support and care available to deal with it.

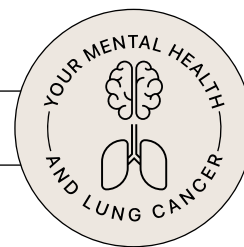
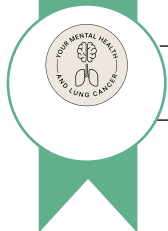
Common emotions following a diagnosis of cancer include shock, **sadness, anger, resentment, guilt, shame, denial, avoidance, confusion, fear, worry, loneliness, stress, depression** and **anxiety**.^{1,5,8,9,10,11} Of course, everyone is different and will experience diagnosis differently. There is no right or wrong way to feel. Difficult feelings can arise at different times for different people. Diagnosis, **recurrence** (your cancer coming back) and the end of treatment are common periods when people may find things more difficult.¹ But, as many as 1 in 4 people also experience psychological difficulties during treatment, too.⁵

Your feelings may change over time.^{8,11}

For example, when you are diagnosed you might experience shock. Later, maybe you will feel sadness as you grieve for your life before cancer, or anger that this has happened to you. Whatever comes up, just allow yourself to feel it and know all feelings are natural.¹¹ Trying to deny or bottle up your feelings could make you feel worse in the longer term and prevent you from accessing valuable support that could help you feel better.¹¹ In **Chapter 3, Helping yourself to feel better**, you can find suggestions for working through emotional challenges.

"It really is a lifestyle change. There are days which are better than others, but learning to slow down has been one of the most difficult aspects to learn to deal with, especially when previous to my diagnosis I was always physically active. In saying this, I'm grateful to be alive and have received the best medical care from the lung team specialists, however, there are still the issues of associated stigmas with lung disease/cancer. I live in hope that one day stigmas will cease to exist!" –

52-year-old with lung cancer, Australia



The feelings of family and friends

It's also common for family and people close to you to experience some psychological distress about your cancer.^{8,10} This is understandable, and at the same time can add another layer to your own negative feelings. For example, you might be worried about them on top of anxieties about your own health.

It might sound like a cliché but talking does help. Telling someone how you feel and discussing the effect cancer has on you both may help you feel more supported and less worried.^{10,11} If talking feels difficult, why not tell people that? In **Chapter 4, Talking about lung cancer** there are some suggestions for things you could say to break down the barriers to communicating. Talking to others with lung cancer – known as **peer support** – can also help, and you can read more about that in **Chapter 6, Support Services**.

Dealing with depression

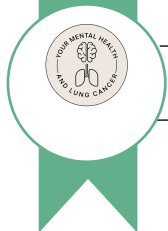
For some people, the suggestions in this guide will not be enough to overcome the psychological distress they feel. Many people with lung cancer develop **clinical depression** or **anxiety**. In fact, it's estimated that up to 65% of people with lung cancer experience depression.¹² It can be hard to diagnose depression in people with cancer, as sadness and psychological distress are common following diagnosis.⁴ However, if you are feeling persistently sad, low, hopeless or disinterested in life, you may have clinical depression, which

can be serious if left untreated. You may also experience physical symptoms, including tiredness, reduced appetite, and aches and pains.¹¹ If you think you might be depressed, speak to your healthcare team about this as soon as possible. In **Chapter 4, Talking about lung cancer**, we offer suggestions to help you do that. Support is available to help manage these conditions. For example, **psychological interventions**, such as **cognitive behavioural therapy**, are proven to be effective in reducing symptoms of depression and anxiety.^{3,4,6,13}

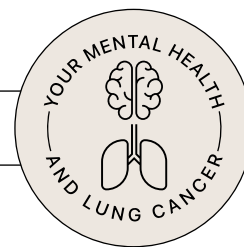
Reasons to feel positive

Lung cancer is not the same disease as it was fifteen, or even ten, years ago. The good news is that, in the last ten years, lung cancer has advanced more than many other cancers in terms of knowledge and treatments that are available.¹⁴ Because of this, many people today live longer with lung cancer than before, with a better quality of life.^{14,15,16} The change is so marked that surviving lung cancer is now a key topic within the medical community. In July 2022, the International Lung Cancer Survivorship Conference (ILCSC) invited people with lung cancer, their supporters and representatives to attend an online educational meeting on living with lung cancer and the scientific advances that have made this possible.¹⁷

For example, in the past, everyone with cancer was treated the same way.^{15,18} Now, for some people, healthcare team can offer more **personalised care**, thanks



YOUR FEELINGS ARE NORMAL

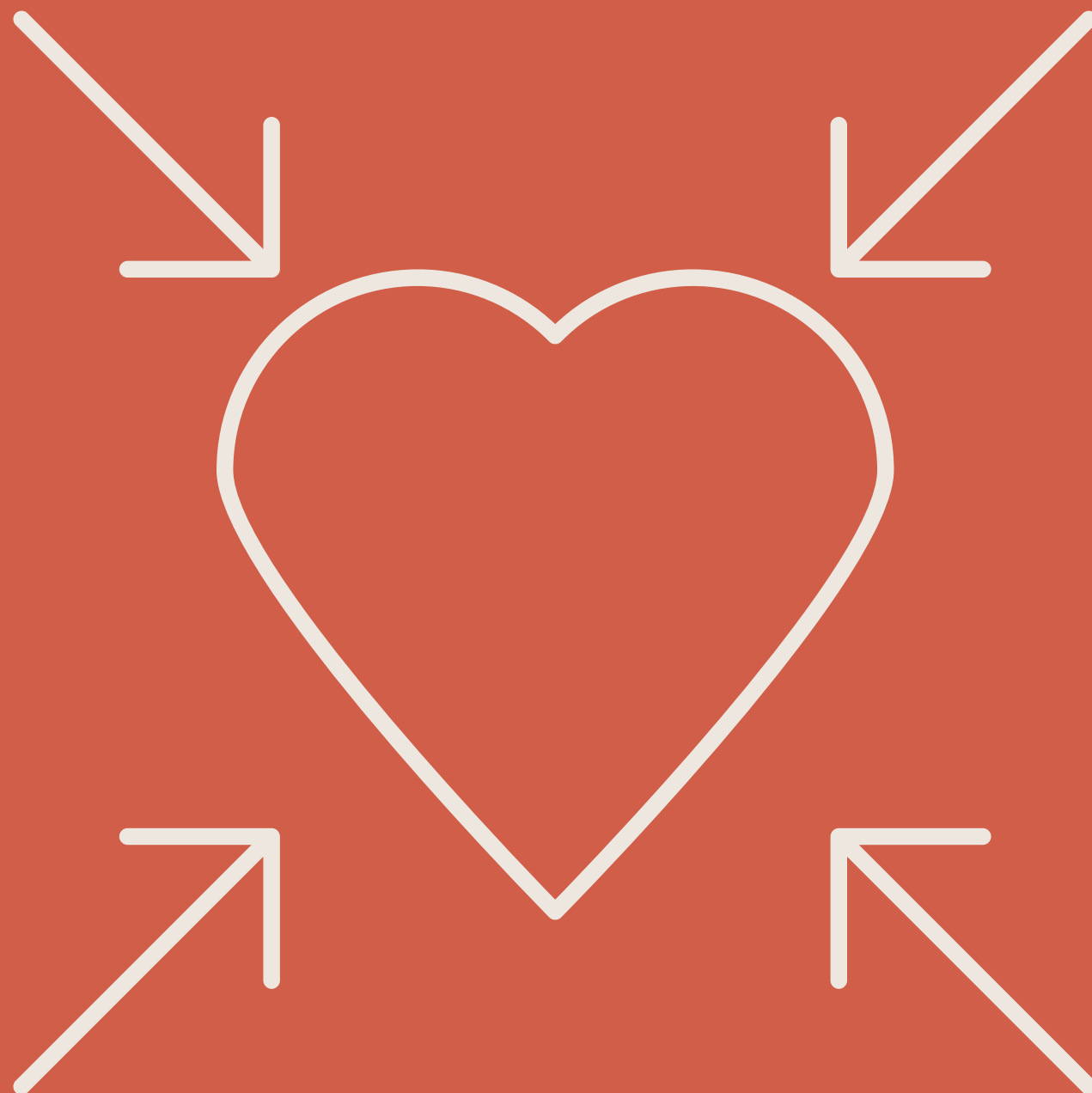
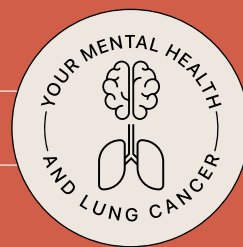


to an approach called **precision medicine**. This tailors the treatment to the individual, meaning treatments have a higher chance of being successful.^{19,20} They also know more about how cancer spreads, and what to do to help prevent that spread.^{14,16} Finding cancer early through screening can also make a real difference to the success of treatments.²¹

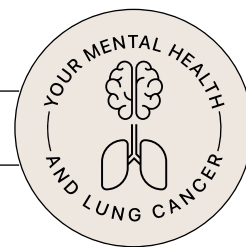
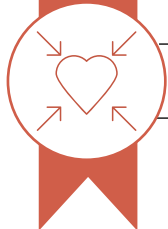
Palliative care has also had a positive effect on how people are living with cancer and how their symptoms are treated and pain managed. Palliative care is often mistaken to mean end-of-life care, but it anticipates, prevents and treats the symptoms and side effects of lung cancer and its treatment. It also helps people with their emotional, social, practical, and spiritual needs, for this reason, is sometimes known as supportive care.²² Evidence shows that when combined with effective treatment, palliative care can reduce anxiety and depression, improve quality of life and help people live longer.^{14,16,23}

"You just have to keep telling yourself it will be better even when you know it's not going to be better. Try to live as normal as possible and never lose faith."

38-year-old with lung cancer, Australia



CHAPTER 03



Helping yourself to feel better

Having coping strategies of your own can help you feel that you can deal with any challenges that arise. You might not be able to get the outside help you need right away, or exactly when you need it – but there are plenty of things you can do to help yourself feel better.

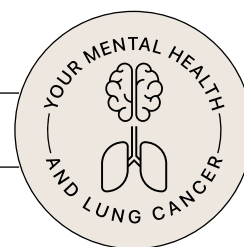
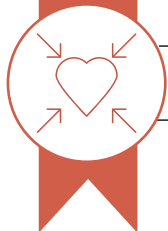
Try including some of the suggestions outlined below in your daily routine. You can refer to these practical tips whenever you need them. Everyone is different and what works for someone else might not work for you, so trying a range of different things is a good approach.

Positive self-talk

The conversations we have with ourselves in our heads are powerful and can affect how we feel. A negative thought often starts as a small seed, and it's the things we tell ourselves routinely that encourage that seed to grow and take root more deeply. This can happen without us even realising it.

On the other hand research suggests positive thinking can help people with cancer. Workshops and repeated practical sessions that focused on positive thinking and positive self-talk have had various benefits, including improved quality of life and resilience,²⁴ feeling more able to cope with cancer²⁵ and a reduction in feelings of hopelessness and suicidal thoughts.²⁶

One technique you could try today is positive affirmations. This is believed to increase positive thoughts and emotions and reduce stress. Changes in the brain have even been seen on brain scans following this technique.²⁷ Positive affirmation involves challenging negative thoughts by repeating a positive statement of your choice every day.²⁷ For example, if you feel you have lost control of your life since you were diagnosed, you could say 'I am in control of how I feel today'. Or go for something even simpler, such as, 'today will be a good day'. The important thing is consistency and repeating the practice daily.



"I am fortunate to feel very well and have an optimistic view of life. I accept my condition but only 'have cancer' on the days when I have an appointment with my specialist, and have treatment or blood tests and CT scans. The rest of the time I lead an active and happy life."

65-year-old with lung cancer, Australia

Meditation and mindfulness

Meditation originated in Asia and is believed to be older than modern civilisation.²⁸ Nowadays, thanks to its many benefits, it's popular all over the world and is often called **mindfulness**. It is often used to help people live with chronic (long term) illnesses and to improve mental health and wellbeing.²⁹ In cancer, it is used to reduce stress, relieve symptoms and improve psychological and physical wellbeing.³⁰ In people with chronic lung conditions, regular meditation has been shown to reduce anxiety and depression.²⁹

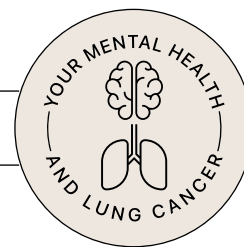
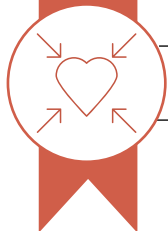
One method is a practice called mindfulness-based stress reduction. It combines four meditation techniques: sitting meditation, body scan, gentle Hatha yoga, and walking meditation.³⁰ Other techniques include visualisation and breathing exercises. Many of these practices are simple to learn and do at home,²⁷ and there are many free apps that can help. See **Chapter 6, Support Services**, for our suggestions for top-rated meditation apps.

There are many ways in which meditation can calm the mind. For example, it can help us to accept whatever situation we are in by giving up trying to control everything and focusing on the here and now. Common techniques include focusing on your breathing or other sensations in the body. Being in the present moment can be particularly useful when the future is unknown and scary, and thinking about the past sparks feelings of regret, guilt or longing. Taking each day as it comes can be the best way to live life with cancer.

Setting goals for your life

The goals you had for your life may have changed since your diagnosis. This can be hard to accept^{31,32} but it can help to see this as an opportunity to make positive changes. While no one would ever want a cancer diagnosis, some people find that it provides an opportunity to reflect on how they have lived their life and to make positive changes for their future. Maybe you are more aware of your health now and want to make healthier lifestyle choices. Or perhaps you have a creative passion or hobby you didn't have time for before because of work. Is there something you have always wanted to see, do or learn? Whatever your situation, now is a great time to start thinking about positive goals for your life, whether related to physical or mental health or your social life.

Evidence shows that making positive changes can help to bring a sense of purpose to life, which we all need.^{24,25}



Setting new life goals may also help you adjust to life after your diagnosis, accept that some things are different now and focus on the positives. This can create a sense of hope. Higher levels of hope have been linked with less depression, anxiety, pain and fatigue in people with lung cancer.³³ It could also help you cope. One study found that 82% of people with treatment-based goals felt confident that they could overcome the challenges of their cancer treatment.³¹

Your goals can be big or small. Small goals are things you can do today, such as going for a walk or eating more vegetables and these can help you to focus on the short term and create a sense of control in your daily life. Bigger goals might require you to think longer term and can give you something to aim for – a reason to keep going on the hard days. Social goals, such as spending more time with friends or family members, or your partner, children or grandchildren, can add to your enjoyment of life and help you reconnect with its value if that's something that's been affected by your diagnosis.

The possibilities for setting goals are endless. Let your mind run wild and try not to allow what you see as your physical or mental limitations hold you back. If you can imagine something for yourself and set your intention to achieve it, you might be surprised by what you can do.

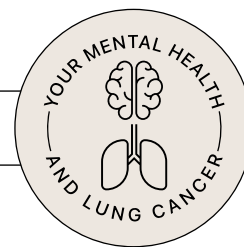
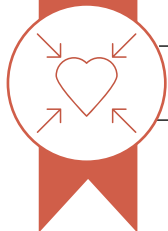
Keeping active

Moving your body has many benefits. It not only benefits you physically, but it also

improves emotional wellbeing, helping to reduce stress and relieve anxiety.³⁴ It can improve sleep, which is vital for feeling well as it's during sleep that our bodies and brains repair.³⁵ While the thought of exercise might feel overwhelming now, a well-designed exercise programme suitable for people with lung cancer can help you cope with your treatments, and reduce fatigue and the severity of other side effects related to your treatment.³⁶ It has also been shown to improve quality of life, mental health, fitness, lung function, muscle mass and strength. Physical fitness, especially strength and good heart and lung function, has also been linked with survival.³⁶

If you can't manage traditional exercise, there are many other ways you can keep active. For example, doing some light gardening or taking gentle walks. Being outdoors has the added benefit of breathing fresh air and being exposed to sunlight, our main source of vitamin D. This vitamin has many health benefits, including regulating immune function, with **the immune system** being our protection against bacteria, viruses and disease.³⁷ Research is ongoing about the role of vitamin D in preventing cancer.³⁸

If you are someone who has been physically active in the past or want to try a recovery fitness programme, speak to your oncologist. Working with a physical therapist can help you find suitable exercises. A gentle programme of breathing exercises, stretching, light aerobic exercise and basic strength training



can be of benefit. Breathing exercises can help improve endurance and make daily activities easier. Stretching your upper body every day will expand your chest cavity and increase your lung capacity, helping with shortness of breath. Aerobic exercise improves heart function and oxygen capacity, which can help with fatigue. Lastly, strength training improves bone and muscle strength, which can be weakened by some cancer treatments.³⁹

Spending time in nature

Our knowledge of the benefits of being in nature is increasing. Research shows being among forests and trees improves mood, sleep and the ability to focus. It can also boost the immune system and reduce signs of stress, lowering cortisol (the body's stress hormone) and blood pressure.^{40,41} Some evidence even shows that being around trees helps people to recover quicker from surgery or illness.⁴²

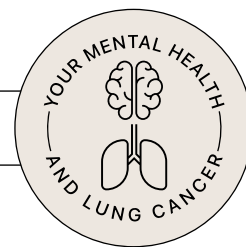
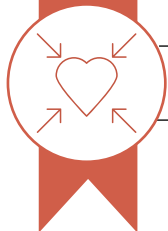
But if you can't visit a forest, other types of nature can have a similar calming effect. Evidence shows spending more time in green spaces, whether a local park, field or garden, can benefit your mental health, mood and life satisfaction. Other people feel similar benefits from being near water, whether the sea, lakes or rivers.⁴² Finding a local community garden project might be a good way to combine being in nature, socialising and keeping active. Gardening has been proven to improve mood, and quality of life, and joining a local garden project can help you feel part of a community.^{42, 43}

To experience the benefits of nature, try to connect with your natural surroundings. You can do this by tuning into what's around you. What can you smell, see or hear? Are there any animals around and what plants can you see? Walking is a great way to enjoy nature, but if you can't manage that, even sitting on a bench surrounded by grass, plants or trees and just watching what's going on around you can help you relax. Nature can teach us important lessons about life cycles and resilience if we are open to it. If nothing else, it could provide a welcome distraction from the daily experiences of diagnosis and cancer treatment.⁴³

Try writing down your thoughts and feelings

Writing things down is proven to help regulate and release emotions and improve physical and emotional wellbeing.⁴⁴ We don't always know how we feel, but writing can help define feelings and could help you to process your diagnosis. Some people find writing their feelings easier than telling them to others, especially if they fear judgement or that they won't be understood. Whether physical or digital, a journal is a safe and private space where you can say anything that you might be reluctant to admit to others.⁴⁵ It also lets you role-play how you might cope with imagined scenarios that could arise in your future so that, if they do happen, you feel mentally prepared.

We're not all natural writers, but writing doesn't need to be elaborate to be



effective. Lists are a good way into writing if it doesn't come easy. For example, you could write five things that have changed for you since diagnosis and see where that takes you. Allow yourself to express how those changes have made you feel.

But you are not limited to writing about your illness. You could try writing a list of things you are grateful for. It doesn't need to be a long list – even identifying one thing you are grateful for can have a positive effect on your state of mind. It can be something small and unrelated to yourself, like a beautiful sunrise or a phone call from a friend. Writing about positive experiences or things we value can make us feel more optimistic and better about ourselves and life.⁴⁶

Below is a list of prompts to kickstart your writing.

- Today, I am feeling...
- I don't like the feeling of...
- Recently, I have been dreaming of...
- I should probably let go of...
- One way I love to spend my time is...
- Cancer is like...

Build a support network

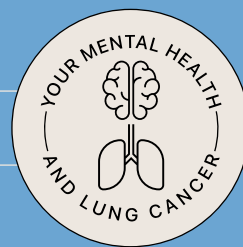
Knowing who you can turn to when you need support can make all the difference in living with cancer.⁴⁶ Your support network could include friends, family members, a private therapist, someone in your healthcare team or other people with lung

cancer. Support can take many forms. It might just be a friend you can message when you need a distraction, someone you can confide in when you need to talk, or someone to provide practical help if you are having a bad day and can't manage your responsibilities.

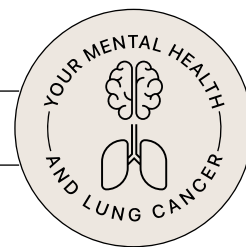
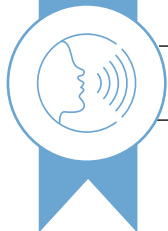
Research shows that people with cancer who feel well-supported are less stressed and feel more able to cope.⁴⁷ Speaking to others who have lung cancer can reduce feelings of loneliness and help you realise your feelings are normal.⁴⁷ There are plenty of online support groups and forums and many people like you, will be looking for someone to talk to about what they are going through. We've included some suggestions in **Chapter 6, Support Services**.

"I wasn't expecting this, I went through depression and anxiety. I had to see the psychiatrist. I spent a lot of time at the hospital and at least the hospital team were there to support me. My worry was about going back home and wondering who would be supporting me there. Joining the cancer support group helped me because I noticed that there are other people who are going through the same things. I have dreams that I still would like to achieve, I can't let cancer cripple me, as I have much to achieve. Mentally, I am focusing on what to achieve and I am using everything to get me to the point where I want to be."

32-year-old mother, diagnosed with stage 4 lung cancer.
South Africa



CHAPTER 04



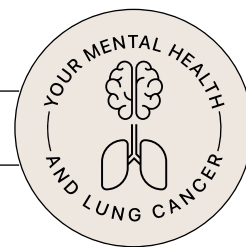
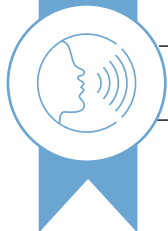
Talking about lung cancer

04

Having resources at your fingertips and a support network is a great help, but there may be times when you need more than this. Talking about mental health doesn't need to be difficult or scary. But because it can be awkward, especially with limited time in your consultations, we've suggested some things you could say to your oncologist to help you access the support you may need:

You could say...

Concerns about yourself	Concerns about family and friends
'I feel overwhelmed.'	'I'm worried about my family.'
'I feel numb / don't know how I feel.'	'I don't know how to tell my friends / family / partner / employers about my cancer diagnosis.'
'I often feel low / anxious since being diagnosed.'	'I am worried about how my cancer diagnosis will affect my partner, family, and / or friends.'
'I can't get past feeling angry.'	'I want to talk to someone about how I feel.'
'I feel judged / guilty for having lung cancer.'	'Is there any support available to deal with my diagnosis?'
'I feel responsible for being diagnosed with lung cancer.'	'Can I have a referral to psychological support services / a psychologist?'
'I feel overwhelmed / anxious / stressed about the pain I'm experiencing – what can I do?'	'Can I have a referral to a peer support group / helpline?'
'I am fearful of dying, is there anything that can help me with this?'	
'I'm struggling to accept my diagnosis.'	
'I have a lot of fear about my diagnosis and what this means.'	

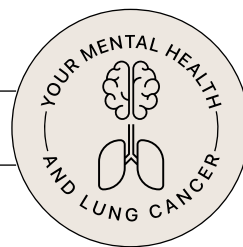
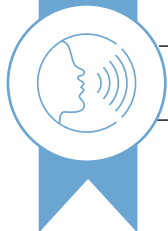


'How can I feel a bit more normal?'	
'What does a new normal look like for me?'	
'How can I begin to enjoy looking to the future again?'	
'How can I reduce my feelings of stress?'	

Opening up to family and friends

Perhaps even speaking to those closest to you is a challenge. Here are some things you could say to a close friend, partner or family member. This includes ideas for when you don't want to talk, as well as when you do. Try to be honest and don't worry about upsetting people. Asking someone for support lets a person know you value and trust them.⁴⁷

- 'It's hard to talk about cancer because I'm worried people won't understand.'
- 'I want to talk, but I don't want to upset or worry you.'
- 'I'm feeling angry / scared / sad / anxious / depressed / overwhelmed since being diagnosed.'
- 'I know my diagnosis has changed life for both of us – shall we talk about it?'
- 'I'm feeling uncertain about the future since my diagnosis – can we talk about it?'
- 'I feel responsible for being diagnosed with lung cancer – can we talk about it?'
- 'I'm worried about the children and how this is affecting them.'
- 'I'm worried about how my diagnosis is affecting you.'
- 'How are you feeling about my diagnosis?'
- 'I think talking to someone I love might help me cope.'
- 'I think it might be good for you to talk to someone.'
- 'I'm finding it difficult to talk about my cancer diagnosis, but I want to try today.'
- 'Today is not a good day for me.'
- 'I don't want to talk about this today.'



Questions you may have

When should I ask for help?

There is no right or wrong time. You should ask for help whenever you feel you need it. Sooner rather than later is usually better, as the longer your distress continues, the worse it can become with a bigger effect on your life.⁴⁸ Remember, you are entitled to this support and no one is going to judge you for needing it.

Who should I ask in my healthcare team?

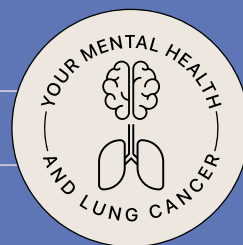
Some people are fortunate to have a mental health specialist working within their healthcare team. If this is not the case, you can ask any of your team for support. They may be able to offer some advice, start a referral or tell you where to find online or local support services, such as support groups, helplines or other information.

What referrals are available?

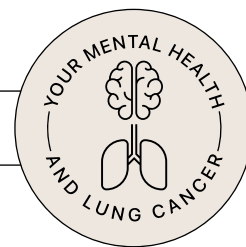
This will vary depending on where you live. Ask your healthcare team for information about support services they can refer you to. You can make a note of this information in the space provided at the back of this booklet.

What referrals are available?

There are plenty of online support groups. Some of these are listed in **Chapter 6, Support Services**. Ask your healthcare team for information about local, support groups you can go to.



CHAPTER 05



Glossary: Explaining some of the language around lung cancer and mental health

Having lung cancer introduces a whole new language to your world. Suddenly, people are using complicated terms about you and your health – most of which is likely to be unfamiliar. This can lead to feelings of confusion and overwhelm you, making it harder to ask for the help you need.

Here, we explain some of the medical jargon you might come across throughout your treatment. This could help you feel less isolated, more in control and able to have better conversations with your healthcare team. We also define the emotions discussed throughout this guide to help you make sense of how you are feeling.

Glossary

A

Anger

A strong feeling of annoyance. It is natural to experience anger towards your situation, and this may be directed at your diagnosis, the lifestyle changes you have had to make, or having to cope with the side effects of treatment. You may also feel anger towards others.¹⁰

Anxiety

A feeling of unease, such as worry or fear, that can be mild or severe.¹¹ See also, **generalised anxiety disorder**.

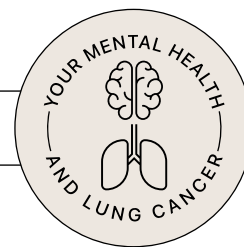
Avoidance

A feeling of wanting to deliberately avoiding; keeping away from or preventing something from happening.

B

Biomarkers

Genes or proteins whose activity becomes altered in cancer, (this is sometimes referred to as a mutation). There are specific biomarkers for cancer present in blood, bodily fluids or tissues. Biomarkers provide important information about a person's cancer that can help guide and potentially improve their care, such as which type of lung cancer is present.⁴⁹

**Biopsy**

The removal of cells or tissue for examination under a microscope by a pathologist. Tissue biopsies are currently the only way to confirm at diagnosis of lung cancer.⁴⁹

C**Cancer stages**

These stages describe where the cancer is in the body, if it has spread, and where it has spread it. When your cancer is first diagnosed, you should be told what stage it is at (and again after treatment has begun - this is called pathologic or surgical staging). Cancer stages range from 0 to 4, with 4 being the most advanced / serious.⁴⁹

Cancer-related fatigue

The feeling of having no energy and no strength to do anything – even getting out of bed can be a challenge. This can be caused by the cancer itself, side effects of treatments and other drugs (steroids or painkillers), or anxiety and depression.⁵⁰

Chemotherapy

Drugs that are used to stop the growth of cancer cells, either by killing them or stopping them from dividing. Chemotherapy can shrink lung cancer tumours, relieve symptoms and extend life.⁴⁹

Clinical depression

A low mood that persists for several weeks/months that impacts daily life.¹⁰

Cognitive behavioural therapy (CBT)

A type of talking therapy that teaches coping skills for dealing with psychological problems. This involves working with a therapist to identify and challenge negative thought patterns and behaviour.¹³

Confusion

A feeling of uncertainty, which may show as irritation, anger, or fear.

D**Denial**

The refusal to accept a situation. This is a common way of dealing with stressful experiences.¹⁰

Depression

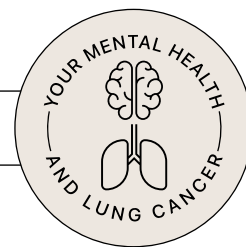
Feeling persistently sad, low, hopeless or disinterested in life. Clinical depression includes physical symptoms such as, tiredness, low appetite, aches and pains. People with severe depression may feel suicidal.¹⁰

F**Fear**

An unpleasant emotion that is caused by the threat of danger, pain, or harm. A cancer diagnosis can often make you to feel frightened and worried about what will happen to you.⁹

G**Generalised anxiety disorder (GAD)**

A long-term condition that causes continuous anxiety about a variety of things. Symptoms can be psychological (affecting the mind) or physical (affecting the body), including feeling restless or worried, unable to concentrate, dizziness or heart palpitations.⁵¹

**Grief**

A term used to describe a collection of feelings that arise following a loss.

Guilt

A feeling of blame and regret that is typically hard to express.

Immunotherapy

A type of cancer treatment that uses drugs to stimulate or suppress the immune system to help it fight cancer when it has spread to areas outside the lung.⁴⁹

Immune system

The bodily system that protects the body from foreign substances, cells, and tissues by producing the immune response and that includes especially the thymus, spleen, lymph nodes, special deposits of lymphoid tissue (as in the gastrointestinal tract and bone marrow), macrophages, lymphocytes including the B cells and T cells, and antibodies.

L**Loneliness**

A feeling of being alone, a state of distress or discomfort that results in a gap between one's desires for social connection and actual experiences of it.

Lung cancer with drive mutations

A change to the DNA of cancerous cells that may have caused the cancer or helped it to grow.⁴⁹

Lymph nodes

Lymph nodes or glands are part of the lymphatic system, a network of tubes and glands that filters body fluid and fights infection and illnesses such as cancer. Cancer cells may be released from a tumour in the lung and then get trapped in nearby lymph nodes.⁵²

M**Metastases**

The spread of cancer from the primary location (where it began) to another area in the body for example, another distant organ, **lymph nodes** or blood

Mindfulness

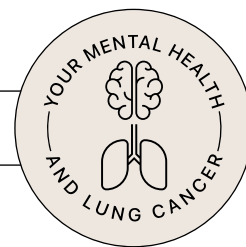
The practice of paying more attention to the present moment – to your own thoughts and feelings, and to the world around you.

Multi-disciplinary team (MDT)

The team of specialists who work together to diagnose, manage and treat your cancer. A lung cancer MDT can be made up of doctors (oncologist and physician), nurses, surgeons, radiologists, pathologists, the palliative care team, occupational therapists, physiotherapists, social workers, clinical psychologists and dieticians.⁵³

N**Non-small cell lung cancer (NSCLC)**

A type of lung cancer that accounts for about 85% of all lung cancers. There are three subtypes of NSCLC, based on the type of cell the cancer develops in. They are adenocarcinoma, squamous cell lung cancer and large cell lung cancer.^{1,49}



O

Occupational Therapist (OT)

Provides advice on adapting your lifestyle, helping you to save your energy while keeping active. The OT can also give you advice on equipment or home alterations to help you.⁵⁴

Oncologist

Doctors who specialise in non-surgical treatments of cancer.⁴⁹

Oncopsychologist

A psychologist who specialises in the mental health challenges faced by people with cancer. They will take into account the psychological, behavioral, family and social aspects of cancer and can support you and your family.

Oncology nurse specialist

Offers specialist lung cancer information and support to patients and their families. You can also contact them directly.⁵⁴

P

Palliative care

Also called supportive care, palliative care anticipates, prevents and treats the symptoms and side effects of lung cancer.

It is complete care that helps with your emotional, social, practical and spiritual needs, with the aim of improving your quality of life with cancer.⁴⁹

Pathologist

Doctors who specialise in identifying diseases by examining tissue samples. They will determine which type of cancer you have and how advanced the disease is.⁴⁹

Peer support

Support provided between people who are in similar positions (for example, other people who have lung cancer). They come together and share their personal experiences to offer understanding, acceptance and all kinds of emotional support.⁴⁶

Personalised care

Personalised care is care or treatment tailored to you. It considers the genetic information of your lung cancer and your lifestyle

and environment.^{19,20} In the past, everyone with lung cancer received the same treatment but as science has advanced that's no longer considered the best approach.¹⁸

Physiotherapist

Helps you maintain or improve your mobility and breathing technique through guided exercises.⁵⁴

Precision medicine (targeted therapy)

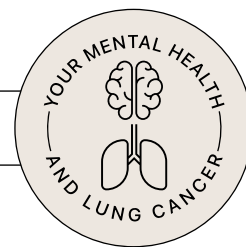
A type of treatment that identifies and targets specific parts of cancer cells, stopping them from growing and spreading. Targeted therapies treat cancer cells only and do not harm the body's normal, healthy cells. Using results from biopsies and biomarker testing, targeted therapy can provide the most effective treatment for you and your specific type of cancer.¹⁹

Progression

The continued growth or spread of cancer.

Psychological distress

Symptoms of stress, anxiety and depression leading to worsening



mental health. High levels of psychological distress are found in people with lung cancer.⁷

Psychological interventions

Non-medicinal interventions or actions performed to bring about change in your behaviours. A wide range of intervention strategies exist and they are directed towards various types of issues. Most generally, it means any activities used to modify behaviour, emotional state, or feelings.

Psychosocial support

Support that responds to the psychological and social needs of you and your family. The psychological element refers to internal emotional and thought processes, feelings and reactions. The social element includes relationships, family and community network, social values and cultural practices.⁵⁵

Psychologist

Can help with a wide variety of emotional and psychological problems, including anxiety, depression and relationship

problems.⁵⁴

Pulmonologist

Doctors who specialise in diagnosing and treating lung diseases. They can also treat breathing problems caused by cancer or its treatment.⁴⁹

R

Rare cancers

Cancers that affect a small number of people. Experts have different ideas about what makes a cancer rare. Some say a type of cancer is rare if fewer than 2 in 100,000 people are diagnosed each year. Others say fewer than 6 in 100,000 people.⁵⁶ In general, lung cancer is not considered a rare cancer. However, certain subtypes are considered rare, such as adenosquamous carcinoma of the lung, (a combination of adenocarcinoma and squamous cell lung cancer).

Radiologist

Performs radiological investigations such as computerised tomography (CT) scans, positron emission tomography (PET), magnetic resonance

imaging (MRI) and bone scans.⁵⁴

Recurrence or relapse

When your cancer comes back after treatment or a period of time when it could not be detected. It may come back in the lung, the lymph nodes or another organ. Fear of recurrence is a common symptom in people with cancer.

Resentment

An uncomfortable feeling of displeasure at something regarded as wrong, or at being treated unfairly.

S

Sadness

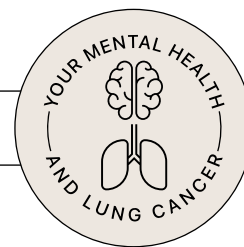
A persistent feeling of unhappiness or grief.

Shame

A painful emotion that results from the belief that you are inferior or unworthy due to one's circumstances.

Side-effects

Unwanted effects of treatment. Typical side effects of lung cancer treatments include: fatigue, infections, stomach problems (nausea, vomiting, diarrhoea, constipation), loss of appetite, hair loss,



and changes in sexual function or fertility.

Small-cell lung cancer (SCLC)

A type of lung cancer that accounts for about 15% of all lung cancers. It usually begins in the airways and is most common in people who smoke (or have smoked). It is very aggressive and spreads quickly. It responds well to chemotherapy but has a high relapse rate.^{1,49}

Social worker

Advises and helps with the practical implications of a cancer diagnosis, including advice on benefits, welfare rights, care at home, childcare and family relationships.⁵³

Stigma

Negative attitudes towards lung cancer and people with lung cancer due to the connection with smoking. Stigma has a serious effect on people with lung cancer. It makes living with cancer even harder as people can feel the need to hide their symptoms, avoid healthcare or blame themselves for their illness.⁵⁷

Stress

An emotion in response to extensive pressure or threat.

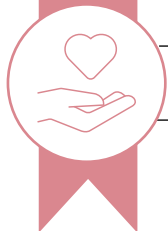
W**Worry**

A feeling of anxiety or unease caused by a given or potential situation.

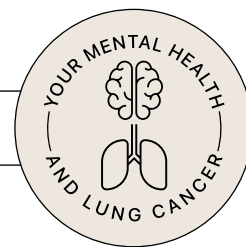
YOU ARE NOT ALONE



CHAPTER 06



YOU ARE NOT ALONE



You are not alone

06

Hearing from other people who have lived through a lung cancer diagnosis and treatment can inspire and give hope to those with a new diagnosis. This chapter is a place you can turn to on those days when you need reassurance or encouragement.

Finding the right support can make your experience of living with lung cancer easier – you are not in this alone and there is a whole variety of people who can help you deal with this. What the ideal support looks like is highly personal. Some people prefer online support, others face-to-face. You could find talking about your feelings easier when you are anonymous, such as in an online chat. Or you may prefer in person,

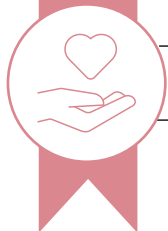
such as through a local support group. Of course, the support services available vary depending on where you live. Ask your healthcare team about local support services and helplines available.

Whatever your prefer, speaking with people who understand what you are going through could help reduce psychological distress. In a patient survey, 30% of people with lung cancer said access to peer support groups would improve their mental health. Some great examples of apps with free subscriptions include [Headspace](#), [Calm](#), [Smiling Mind](#), and [Untire](#).

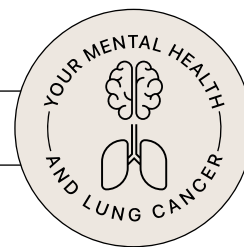
Online peer support groups

Online groups, such as those listed below, can be a good place to start, giving you instant access to a wide range of support.

- Lifeline LUNgevity: peer-to-peer support – www.lungevity.org/for-patients-caregivers/support-services/peer-to-peer-mentoring
- War on Cancer: peer-to-peer support and chat forums – waroncancer.com/our-story
- Other online support systems, such as closed Facebook groups, WhatsApp channels, and other social platforms, might help you feel connected



YOU ARE NOT ALONE



Telephone support

Many local organisations in your country will also have phone services, known as helplines. In the UK, some available helplines include the following.

- LUNgevity: free lung cancer helpline in English and Spanish – **844-360-5864**
www.lungevity.org/for-patients-caregivers/support-services/lung-cancer-helpline
- Macmillan: telephone buddy support line – www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/telephone-buddies
- Macmillan Support Line – **0808 808 00 00**
- Worth the Fight: telephone buddy support system – www.go2foundation.org/resources-and-support/emotional-support/phone-buddy

Finding information online

Not everything you read online is reliable or current. It is best to avoid searching Google for answers. Even information comes from a reliable source, it's important to check when it was last updated to make sure it's not based on 'old science'. Lung cancer is an area that is rapidly evolving and so

information becomes outdated quickly.

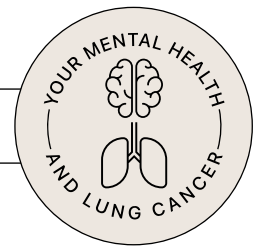
Patient representative groups, charities and global organisations provide trustworthy, accurate information. You can also ask your healthcare team for sources of reliable information or check the list below.

Lung cancer information sources

- ALK+ UK – www.alkpositive.org.uk/
- Cancer Association of South Africa (CANSA) – www.cansa.org.za/
- Cancer Support Community resources – www.cancersupportcommunity.org/lung-cancer
- The Israeli Lung Cancer Foundation – www.ilcf.org.il/about-ilcf/
- 'Frankly speaking about cancer' podcast 'inspiring people to live well with cancer' – www.podcasts.apple.com/us/podcast/frankly-speaking-about-cancer-with-the-cancer/id419668327



YOU ARE NOT ALONE



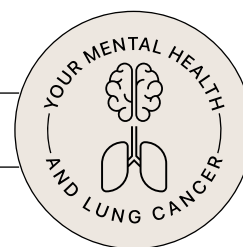
- Global Lung Cancer Coalition – www.lungcancercoalition.org/
- GO2 Foundation – www.go2foundation.org/
- Lung Foundation Australia – <https://lungfoundation.com.au/>
- Lung Cancer Europe – www.lungcancereurope.eu/
- LUNgevity Foundation – www.lungevity.org/
- Lung Health Foundation – www.lunghealth.ca/
- International Association for the Study of Lung Cancer (IASLC) – www.iaslc.org/
- Selbsthilfe Lungenkrebs (Self-Help Lung Cancer) – www.selbsthilfe-lungenkrebs.de/
- The American Lung Association – www.lung.org/
- Unidos Contra el Cáncer – www.standuptocancer.org/es/
- WALCE – www.womenagainstlungcancer.org/en/home-english/

Mental health information sources

- Mental Health America (MHA) – www.mhanational.org/
- Mind – www.mind.org.uk/
- National Alliance on Mental Illness (NAMI) – www.nami.org/Home
- National Institute for Mental Health (NIMH) – www.nimh.nih.gov/
- NHS Better Health - Every Mind Matters (OHID) – www.gov.uk/government/news/new-every-mind-matters-campaign-to-improve-peoples-mental-health

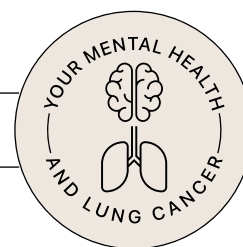
Apps

- FearTools – www.feartools.com
- Mindfulness apps, such as Calm, Headspace, Insight Timer – available on Google Play and Apple App Store
- Untire fatigue management app – www.untire.me/

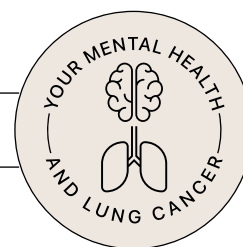


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