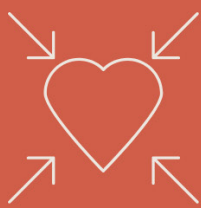
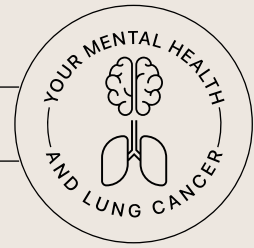




Promoting good mental health in people with lung cancer





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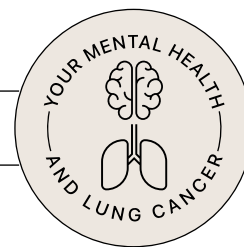
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01 Introduction

Evidence shows that around 60% of people with lung cancer experience **psychological distress**.¹ The **stigma** surrounding lung cancer contributes to this high prevalence rate.^{1,2,3}

Better mental health has been linked to improved lung cancer outcomes,^{2,4,5} so working to ensure people with lung cancer receive the psychological support they need is important.

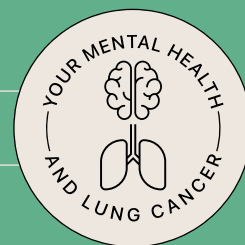
The point of diagnosis represents an opportunity to address the mental health impact of lung cancer. Talking to people about the disease and their response to diagnosis is the first step. By doing so, you help to break down stigma around mental health and lung cancer and open access to the wide range of support provided by your multi-disciplinary team (MDT).

This guide aims to make those conversations easier and facilitates referral to expertise within the MDT. Promoting good mental health in your patients with lung cancer, from the point of diagnosis and beyond, will give them the best chance of living well with cancer.



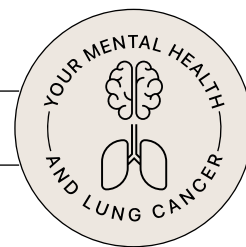
Next chapter:

Glossary of important information



Glossary of important information

Here, we revisit common terminology you can expect to face during a patient's lung cancer journey. You can use these definitions to facilitate communication with your patients on how they are feeling.



A

Anger

A strong feeling of annoyance or hostility. This is a prevalent emotion in people with lung cancer due to the substantial changes that occur in their life throughout their diagnosis and treatment journey.⁶

Anxiety

A feeling of unease, such as worry or fear, that can be mild or severe.

Avoidance

The action of keeping away from a situation.

C

Cancer-related post-traumatic stress

Cancer-related post-traumatic stress mirrors traditional post-traumatic stress disorder, with the person experiencing feelings of shock, fear, helplessness, or horror.⁷

Clinical anxiety

Excessive feelings of unease, fear, tension, and worried thoughts, which impact daily activities.⁸

Clinical depression

A low mood that persists

for several weeks/months that impacts daily life.⁸

Confusion

A feeling of uncertainty surrounding a certain situation.

D

Denial

The refusal to accept or accept a situation. Denial is a prevalent emotion in people with cancer and, from a psychoanalytical viewpoint, is a pathological, ineffective defence mechanism.⁶

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.⁶

Disease recurrence

Lung cancer that has come back after a period of time during which cancer could not be detected.⁹

F

Fear

A feeling caused by the threat of danger, pain, or harm.

G

Guilt

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

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.

P

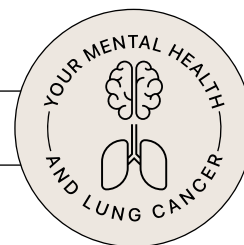
Psychological distress

Symptoms of stress, anxiety and depression leading to impaired mental health.¹⁰ High levels of psychological distress are found in people with lung cancer.¹

R

Recurrence or relapse

When your cancer comes back after treatment or a



period of time where 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.

Self-management

Multicomponent behavioural strategies that focus on the monitoring and regulation of behaviours and reinforcements.¹¹

Shame

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

Shock

A sudden and overwhelming feeling triggered by an upsetting or surprising situation

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 symptoms, avoid healthcare or blame themselves for their illness.¹²

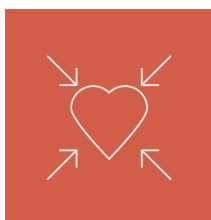
Stress

An emotion in response to extensive pressure or threat.

W

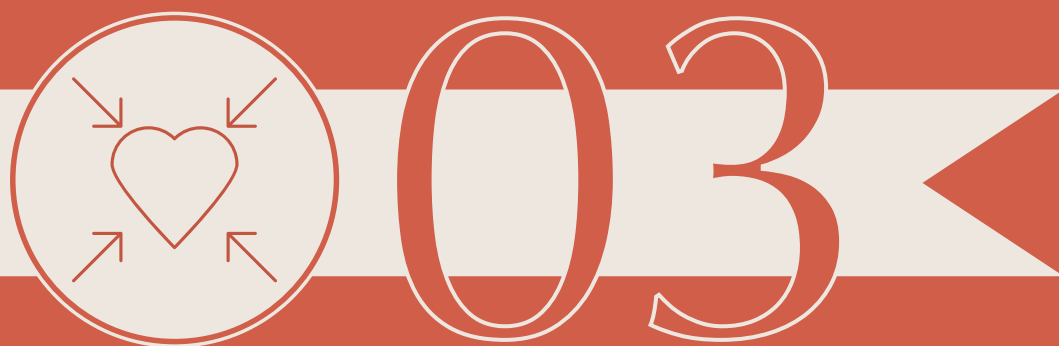
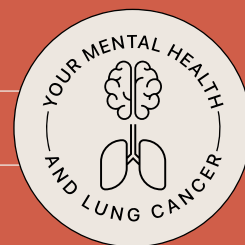
Worry

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

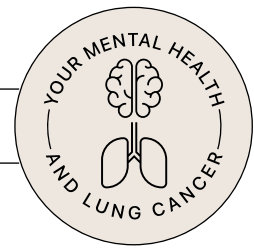
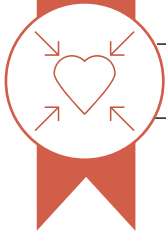


Next chapter:

Psychological distress and lung cancer



Psychological distress and lung cancer



Psychological distress and lung cancer

Lung cancer has profound secondary effects on a person's emotional, social and spiritual wellbeing.³ **Psychological distress** is more common in lung cancer than in other types of cancer due to the **stigma** around the disease.^{2,3} People may blame themselves for their cancer if they have a smoking history and may even believe they are undeserving of the support that is available to them.^{2,13,14} As a result, support needs in people with lung cancer may be greater than for other types of cancer.^{15,16}

Evidence shows around 60% of people with lung cancer experience psychological distress, while 43% have **clinical depression** and 17% **clinical anxiety**.³ Psychological distress can occur at any time. Common emotions following a cancer diagnosis include **shock, sadness, anger, resentment, guilt, shame, denial, avoidance, confusion, fear, worry, loneliness, stress, depression** and **anxiety**.^{1,6,8,16,17} **Recurrence** and the end of treatment are trigger points for psychological distress,¹⁸ while, as many as 1 in 4 people experience depression or other psychosocial problems during treatment, too.¹⁶ Support needs vary from person to person and the nature of the distress experienced is also likely to evolve depending on the stage of a patient's disease.¹⁹ For example, in the palliative care setting, depression, severe grief reactions, and demoralisation are common.³

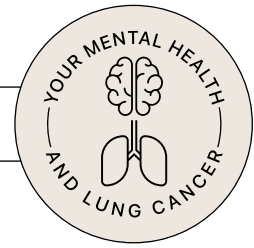
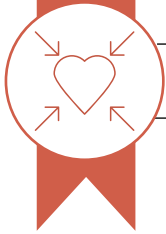
Psychological distress can affect the entire family

It's not only people with lung cancer who suffer due to their diagnosis; often there are wider support needs among family members. Psychological distress in patient supporters (carers), spouses and children of the person with cancer is common and may be equal to or greater than in the person with cancer.²⁰

Research suggests up to half of patient supporters' experience significant anxiety and depression that often persists beyond the point of diagnosis.²¹ However, psychological support services are underused; this type of support is often seen as a last resort and people wait until circumstances become unbearable before seeking support, highlighting a need to normalise these issues and their treatment.²¹ Meanwhile, children of people with cancer often experience emotional or behavioural problems, with adolescent girls being particularly at risk of anxiety and depression.²² Some studies have shown up to 21% of boys and 35% of girls between the ages of 11-18 report clinically significant **post-traumatic stress** symptoms.²²

Talking about mental health

Despite its prevalence, people can find it challenging to talk about mental health. Your role is fundamental in helping to empower people with lung cancer to speak up about their mental health challenges so they can receive treatment or support



to help them cope. One way you can do this is by normalising such problems, for example, by letting people know about the common reactions to the diagnosis we've described above. Another is telling them they are free to talk about how they are feeling whenever they need to.

Raising the topic of mental health and psychological distress with your patients early on helps to break down any perceived barriers around the appropriateness of talking about these topics in consultations. People may believe you can only help them with the treatment or management of cancer. Letting them know that there is a whole team of people available to support them throughout their lung cancer journey can help and may help them to open up about psychological support needs.

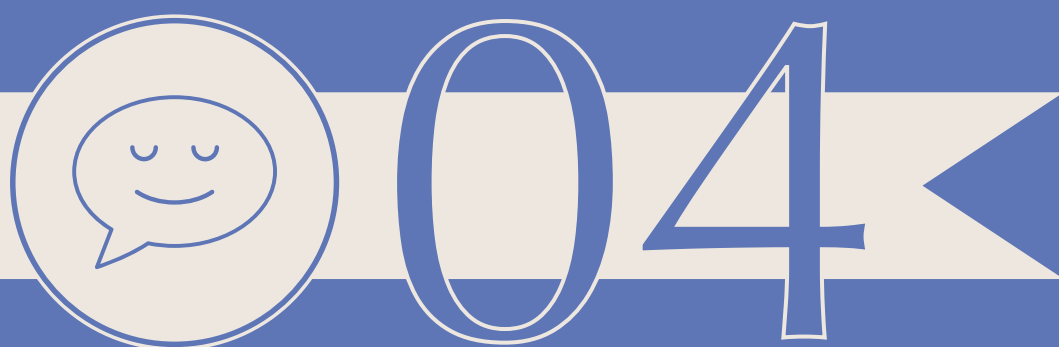
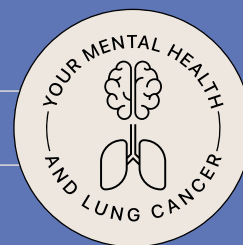
You'll find more advice about how to talk to people with lung cancer about their mental health in this guide.

See **Chapter 4, Talking to people with lung cancer about mental health** and **Chapter 5, Principles of good communication.**

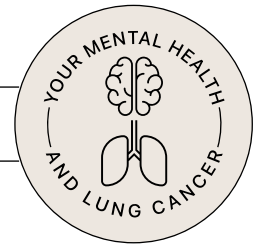


Next chapter:
How the MDT can help





How the MDT can help



It takes an entire team with mixed expertise to manage lung cancer effectively. Working together with your MDT not only results in the best care for people with cancer, but it can save you time and fosters positive working relationships. Most importantly, working together to prioritise mental health in people with cancer could lead to better treatment outcomes.^{2,4,5,23} Evidence shows that treatment for psychological distress improves outcomes for people with cancer, including:

Earlier diagnosis and optimal treatment

A study of 50,000 veterans with lung cancer and mental illness found those who received mental health care and social support were more likely to receive a diagnosis at an earlier stage and to receive optimal treatment at any stage.⁵

Improvements in survival

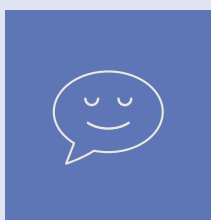
The same study found those who received mental health treatment lived substantially longer than those who did not. A reduction in cancer-related deaths of 23% was observed.^{4,5}

Better quality of life and fewer symptoms

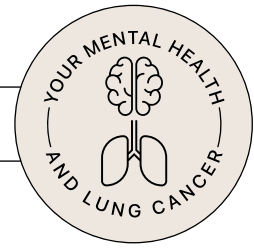
Treatment for severe depression in people with cancer has also been shown to improve quality of life and reduce symptoms such as pain and tiredness vs no treatment.²⁴

Who is in your MDT?

To make the most of the MDT's expertise, it's important to know which services are available within your hospital and community. Having this information on hand can help to maximise the efficiency of referrals when required.



Continue over the page to see what services your hospital can provide:



What services can your hospital provide?

Does your hospital provide specialist services to meet a variety of patient needs? What are they? Do you have named contacts within these departments and an efficient means for initiating a referral to these services? For example:

- Psychologist
- Onco-psychologist
- Psychosocial support
- Palliative care
- Pulmonary rehabilitation
- Physiotherapist
- Dietician
- Occupational therapist

What services can your community provide?

Are you aware of services available in your local community? If not, is there a way you can find out about this vital support for people with lung cancer? For example:

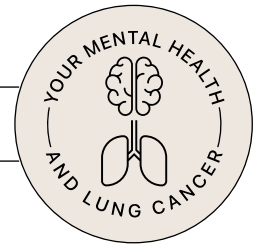
- Local peer support groups
- Financial advice
- Mental health crisis services
- Translation support services

Online information

Are you aware of which websites are reliable sources of information to refer people with lung cancer to? Think about information and support needs. For example:

- Websites providing information about mental health and its treatment
- Website providing up-to-date quality, and trusted information on lung cancer, such as those run by patient organisations: e.g., Lungevity, LUCE, and GLCC
- Online peer support networks or online chats for people with lung cancer

Being able to provide information on these services can make a big difference to people with lung cancer, who are unlikely to have all of their questions or needs answered in one consultation.



Supporting patients to support themselves

Since the referral process for psychological support can take time, giving people tools to self-manage their mental wellbeing can be a good short-term solution. This includes free subscriptions to digital options, such as [Headspace](#), [Calm](#), [Smiling Mind](#), and [Untire](#). For some people, these strategies may provide sufficient support, without the need for a referral.

A systematic review of RCTs found that self-management interventions had a positive impact on anxiety and depression, quality of life and symptom burden. Improvements were observed in fatigue, sleep quality and capacity to exercise. Increased treatment effects were also observed in certain people with lung cancer.²³

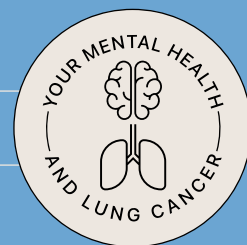
Support services check list

The support services available to people with lung cancer are extensive, as highlighted throughout this section, and it can sometimes prove challenging to recall which services are readily accessible to your patients. Below is a checklist for you to complete regarding the support services that might be available in your hospital, your community, and online.

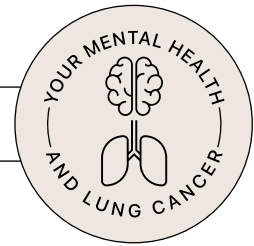
My hospital can provide:	My community can provide:	Key websites:
<input type="checkbox"/> Palliative care <input type="checkbox"/> Pulmonary rehabilitation <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Occupational therapist <input type="checkbox"/> Psychologist <input type="checkbox"/> Onco-psychologist <input type="checkbox"/> Psychosocial support	<input type="checkbox"/> Translation support services <input type="checkbox"/> Local support groups <input type="checkbox"/> Financial advice	<input type="checkbox"/> Information sites, e.g. government funded websites <input type="checkbox"/> Patient organisations, e.g. Lungevity, LUCE, and GLCC <input type="checkbox"/> Mental health crisis services



Next chapter: [Talking to people about mental health](#)



Talking to people about mental health



Talking about mental health is important to people with lung cancer, however, not everyone is comfortable discussing these topics, and that includes healthcare professionals.

And even if you are comfortable, consultations are short: it can be difficult to cover all the essentials relating to symptoms and treatment within the allotted time, let alone other equally important aspects of a person with lung cancer's care, such as mental health. For these reasons, below you can find some suggestions to help you raise the topic of mental health efficiently and sensitively, and if necessary, to initiate a referral to the most appropriate member of your MDT.



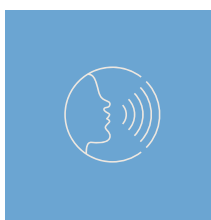
How can you broach the topic of mental health?

To open the conversation, you might say...

"I'm here to treat and manage your lung cancer and its physical symptoms and can answer any questions you might have about that. But I'm aware you might have other questions or concerns around your diagnosis."

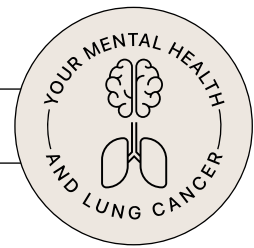
"While I might not be able to help with everything, there is a whole team here to support you. For anything I'm not able to help with, I can refer you to someone with the expertise to help."

You can follow this up with some specific questions that relate to what you know about your patient. For example, are they newly diagnosed, about to start or have recently started treatment, or are they experiencing some unpleasant side effects? Consider how your patient appears that day and what might be the most appropriate question to ask. Perhaps a general 'how are you feeling today?' is enough to initiate a conversation about psychological difficulties.



Continue over the page to see
What Questions you could ask:





Questions you could ask:

- How are you feeling today?
- How are you feeling about your diagnosis?
- Are you feeling worried about starting/stopping treatment?
- Many people have fears about the effects of treatment or cancer progression. Is this something that you are worried about? (Would you like to talk about this today?)
- Being diagnosed with cancer can be overwhelming for many reasons. It can be helpful to talk to someone about how you are feeling. Would you like me to refer you to someone who could help?
- Would emotional or practical support be helpful?
- It might be helpful to talk to someone about how you are feeling. Would you like me to refer you to someone who could help?
- Are you able to talk to peers or loved ones about your feelings?
- Would you like me to put you in touch with a telephone support line or online support?
- Would you like more information on your treatment/available support/ideas for supporting yourself through this time?

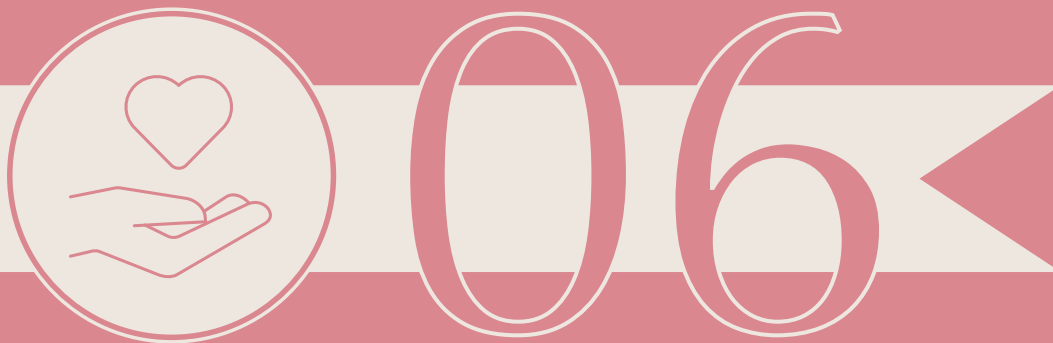
When to ask your patients about their mental health

Asking your patients how they are feeling is not a one-time requirement. A person's feelings about their lung cancer are likely to change over time – as can their willingness to discuss any difficulties that arise. Psychological distress can affect people at any time throughout a cancer journey. Checking your patients' psychological support needs at regular intervals is necessary. Key times to ask include at diagnosis, before starting treatment, during treatment, before stopping treatment, and when cancer recurs.^{6,16,20} But there is no wrong time to ask. Letting your patients know that they can raise this topic with you or other MDT team members whenever they feel the need is also a good idea.

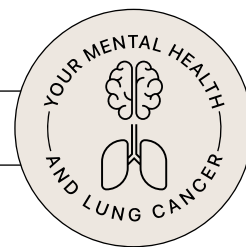
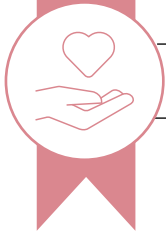
For further information on screening for and managing anxiety and depression in adults with cancer, please refer to the [ESMO Clinical Practice Guidelines](#).



Next chapter: **What makes good communication?**



What makes good communication?



The words you use to broach sensitive topics, like mental health, can make a difference to a person's willingness to engage or open up. In fact, evidence suggests language used in a healthcare setting can have a profound impact on patient outcomes.²⁵ This is particularly important in lung cancer, where stigma is still such a problem.

The lung cancer community is increasingly aware of the importance of language as an aspect of patient care. For example, the International Association for the Study of Lung Cancer (IASLC) has developed best practice guidelines for communication which promote the use of language that is respectful, free of stigma, inclusive, and equitable.²⁶

Below, you can find some guiding principles of good communication which align with advice from the IASLC and ASCO, as well as a **lexicon guide** for specific examples of person-centred language.

Good communication guide

Use person-first language. This means putting the person before their disease. People are more than their cancer diagnosis and should not be defined by that; doing so dehumanises them and removes their identity. If in doubt, just remember, to talk to people like they are people, not patients.^{26,27}

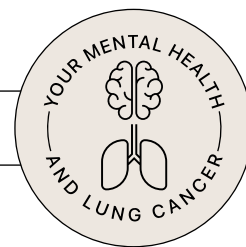
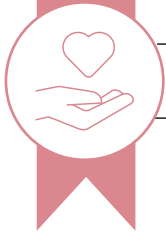
Eliminate blame language. The medical lexicon is rooted in a tradition, but certain phrasing is outdated and should be evolved. Try to ensure your language is free of blame, non-judgemental, and empathic.^{25,26,27}

Avoid stigmatising language. The aggressive yet effective tobacco control health policies and messaging have unfortunately led to an increase in

smoking-related stigma. Using judgment-free language when speaking to people with a smoking history is important for reducing this stigma of lung cancer.²⁶

Be respectful. Practice cultural humility and sensitivity by following best practices regarding race, ethnicity, gender, and socioeconomic status.²⁶ And don't forget to respect the role of people with lung cancer – doctors do not manage patients; doctors manage diseases/therapies.²⁷

Avoid jargon. Health literacy in the non-medical community is low. For example, in England, 42% of working-age adults are unable to understand and make use of everyday health information.²⁸ Where possible, avoid complex language and take care to explain technical terms when



they cannot be avoided. Consider writing technical terms down (e.g. metastasized). This will enable people to affirm understanding or read more about this in their own time if they wish to.

Check the person's understanding.

If you've just explained something complex, always ask if the person has any questions or whether they need any additional information.

Do not dismiss your patient's concerns.

Avoid language that could make a person feel dismissed, such as, 'I don't have time to explain this today'. Consider how that could feel given how long a person may have waited to speak to you.

Ask your patient what kind of language they prefer or follow their cue.

Different people have different preferences about the language they use to describe cancer. For example, for some people, 'fighting cancer' may feel empowering, while to others, the idea of winning or losing a fight can introduce feelings of blame or shame.²⁹

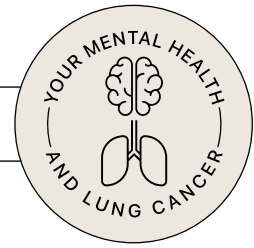
Timing is important. Someone with a new cancer diagnosis will have different information needs and possibly a lesser ability to comprehend certain details related to cancer and its treatment than a person who is further along their disease journey.

Don't overload your patients with information. Evidence shows cognitive overload reduces a person's ability to comprehend or remember what they have been told.³⁰ Consider how you can break information into bite-sized chunks that are easy to digest. Ask yourself, what information is essential for this individual today?

Encourage questions. Encouraging questions can be a good way of measuring a person's information needs. It can also empower people by helping them to feel involved and in control of their care.

Non-verbal communication. Consider your body language when you are talking to your patients. Are you making eye contact? Non-verbal communication conveys how present and engaged you are and is as important as your words. You can also detect important cues about someone's emotional state from their body language. For example, twitching or trembling fingers can indicate anxiety, while clenched fists can show someone is angry.³¹

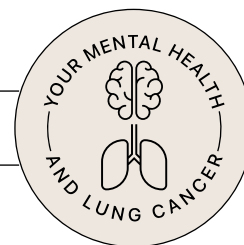
Delivering bad news. The idea that there is no good way to deliver bad news is a myth. How, when and where you deliver bad news is important. Ideally, communication should be face-to-face and the person should have a friend or relative present. Choose somewhere private and quiet and give the person time to react and ask questions, without feeling rushed.



Lexicon guide for person-first language

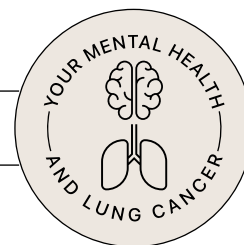
What to avoid, and what to say instead

Avoid	Say
Treatment failure	Treatment was not effective / stopped working
Patient failed treatment	Treatment failed patient
Refused treatment	Decided against treatment / declined treatment
There is no cure	There are treatments that can slow cancer progression
Complains of	Experiences / reports
Lung cancer patient	Person with lung cancer
Lung cancer survivor	Survivor of lung cancer
Smoker	Person with active tobacco use / person who smokes
Ex-smoker	Person with a smoking history
Non-compliant	Unable, not able to; Chooses not to
Carer	Patient supporter
You don't understand	Lung cancer can be very hard to understand



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This material was developed by the Global Lung Cancer Patient Council and supported by Roche. It is provided to patient organisations for their use and adaptation and Roche accepts no liability once adapted.

With special thanks to...

Aileen O'Meara – Advanced Nurse Practitioner in Oncology, St. Vincent's University Hospital

Alexandra Nunez – Unidos Contra el Cancer

Anne-Marie Baird – Lung Cancer Europe (LuCE)

Christian Schmitt-Plank – Selbsthilfe Lungenkrebs (Self-Help Lung Cancer)

Debra Montague – ALK Positive UK

Elizabeth de Jong – Go2 Foundation

Juanita Segura – Go2 Foundation

Mark Brooke – Lung Foundation Australia

Peter Glazier – Lung Health Foundation

Shani Shilo – The Israeli Lung Cancer Foundation

Stefania Vallone – Women Against Lung Cancer in Europe (WALCE)

Vivek Tomar – Rise To Survive Cancer, India

Zodwa Sithole – Cancer Association of South Africa (CANSA)

