Talk Lung Cancer...

Mental health:
A handbook for patients

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Overview

Living with lung cancer can have a significant impact on mental health – from diagnosis through to remission and beyond.

This handbook aims to provide supportive information about mental health, for patients at any stage of their lung cancer journey. Family, friends and carers of someone with lung cancer may also find this handbook useful, to better understand what their loved one is going through.

Please note that the information in this handbook **should not be interpreted as medical advice** and is intended for guidance only.

The handbook covers the following topics, with suggestions for coping mechanisms around each one:

- Scanxiety
- Stigma
- Loneliness of rare types of lung cancer
- Lung cancer and young people
- Mental health during treatment
- Anxiety and depression during remission
- Living with advanced lung cancer
- Carer's mental health

The above is not an exhaustive list of mental health challenges a patient may face, and not all suggestions for coping strategies will apply to everyone.

Please remember that emotional wellbeing is important and support is available; you do not have to cope on your own. While stigma sadly still exists around mental health issues, you should feel able to seek help without fear of judgement.

There are people and organisations available to support you, and your healthcare team is there to help you throughout your lung cancer diagnosis and beyond. Your care team is likely to be multidisciplinary, bringing together professionals from different specialties, including those who support mental and emotional wellbeing, such as psychologists, psychiatrists, or counsellors. You may also find it helpful to talk with your closest friends, family members or loved ones about your diagnosis and how you're feeling.

You may also find it helpful to read this handbook on living well with lung cancer, which contains information and advice around practical sources of stress such as work and financial issues, and the multidisciplinary team that will support you with different aspects of your care.

If you're in immediate crisis or feel unable to cope, you can contact your GP, NHS 111, or Samaritans on 116 123 for urgent support.

For further support, you can call the Roy Castle Lung Cancer Foundation's helpline on 0800 358 7200.

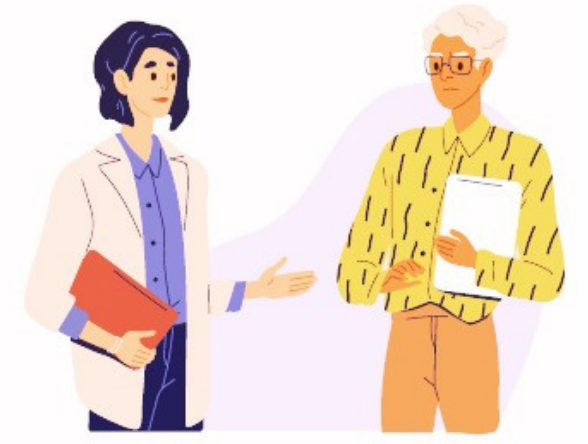
Scanxiety

Scanxiety is a term used to describe the anxiety and emotional distress that some people may feel before, during, or after medical scans. This form of anxiety is common among many people living with lung cancer, and it can significantly affect quality of life.[1]

You might experience scanxiety because:

- You're waiting for the results of a scan to see how far the cancer has progressed
- Scan results will help you to understand if your treatment is working
- You're in remission for lung cancer, and are undergoing a scan to see if it has returned

Scan results can take a while to be communicated to you because the findings need to be reviewed and processed by your doctor, and possibly discussed amongst your wider healthcare team, beforehand. Waiting for results can feel unbearable. If the waiting period is causing you significant distress, speak to your healthcare team as they are there to support you.



Strategies for coping with scanxiety:

- Keep a ‘scan plan’ with appointment dates, questions you have, and topics to discuss when you receive your results. This can help you to feel more in control of the scan. See the next page for a template scan plan you can use
- Inform your healthcare team about your scanxiety if it is becoming overwhelming, as they may be able to offer support, refer you to additional services, or they could adjust how they communicate your scan results if a certain communication method increases your anxiety
- Find ways to distract yourself when you’re feeling anxious. This might include puzzles, watching a funny TV show, crafting, reading, listening to music, gardening, cooking or engaging in any hobbies that you enjoy which will help divert your attention
- Practice mindfulness techniques and breathing exercises to reduce anxiety. Some people find the ‘5-4-3-2-1’ grounding exercise helpful to interrupt anxious thought cycles. This involves looking around you and focusing on:
    - 5 things you can see
    - 4 things you can touch
    - 3 things you can hear
    - 2 things you can smell
    - 1 thing you can taste

Scan plan template

	Scan 1	Scan 2	Scan 3
Appointment date			
Type of scan			
Location			
Feelings before the scan			

Scan plan template

	Scan 1	Scan 2	Scan 3
Questions to ask before the scan			
Topics to discuss during results appointment			
Feelings after hearing the results			
Coping strategies			

Stigma

A diagnosis of lung cancer can be overwhelming in itself, but many people face additional mental strain due to the stigma – or shame – associated with smoking. Despite 15% of lung cancers being diagnosed in people who have never smoked, sadly, research has shown that people attribute more stigma to lung cancer than breast, cervical, colorectal and skin cancer.[2,3]

This might result in you feeling judged or blamed for your illness, with questions like “Do you smoke?” often implying that you’re somehow responsible. Stigma may also impact how you interact with your healthcare team. Even if unintentional, certain comments about smoking made during appointments might make you feel ashamed or uncomfortable.

Please remember that everyone with cancer deserves to be treated with compassion, regardless of their smoking status, and that nobody should feel criticised or blamed.

It’s also important to recognise that cultural factors, such as class, age, cultural background, sexual orientation, gender norms, or language, can shape how stigma around mental health, illness, and bereavement is experienced, and some people may face additional barriers because of these differences.

Strategies for dealing with stigma:

- Write out a list of ways you could respond to people who display judgement towards you, to help you feel prepared for uncomfortable conversations
- Set boundaries with people who make insensitive comments, by telling them how it makes you feel, or reducing your contact with them
- Find safe spaces that are free from judgement. This might be via online forums, or through a local lung cancer support group
- Read books or online articles about how others may have faced and coped with similar situations
- Talk openly to your loved ones about the impact of stigma. Honest communication can help to build trust and support

Loneliness of rare types of lung cancer

While lung cancer is the third most common cancer in the UK, there are rarer forms of the condition that fall within the definition of lung cancer.[4] These less common types include lymphomas, mesotheliomas, neuroendocrine tumours, sarcomas, and some lung cancers driven by less common genetic changes that occur in a small number of patients.[5,6]

If your type of lung cancer is rare, you might face worry and anxiety if standard treatments are not suitable for you. You may also struggle to find information about your particular type of cancer, or you might feel isolated if your condition isn't represented in public conversations about lung cancer.

This can take a toll on your mental health, so it's important that you receive tailored support and feel able to talk openly about how you feel.

Strategies for coping with loneliness or anxiety if you have a rare type of lung cancer:

- Ask your doctor about treatment options that may be relevant to your specific diagnosis. There is no one-size-fits-all when it comes to lung cancer treatment, and it's important to have all the options explained to you

- Talk to your healthcare team, such as your cancer nurse specialist, to get reliable, personalised information and guidance

- Make use of trusted online resources by NHS websites, and patient organisations like the Roy Castle Lung Cancer Foundation. There are certain charities that specifically support people whose lung cancer is driven by certain genetic mutations such as EGFR Positive UK, ALK Positive, the Ruth Strauss Foundation and ROS1ders UK

- Seek out peer support by connecting with others who have similar or rare types of lung cancer. The Roy Castle Lung Cancer Foundation hosts a community forum and online support sessions tailored towards a variety of topics related to living with and managing lung cancer

Lung cancer and young people

Lung cancer is often thought of as a disease affecting older people, but this isn't always the case. While it's true that nearly half of people diagnosed in the UK are over 75, lung cancer can affect young people too – and in those who have never smoked, it's actually more common in younger age groups.[7]

If you're a young person with lung cancer, you may face particular challenges that the average patient doesn't – from worries about relationships and fertility, to caring for children or older relatives, disruption to your studies or work, and financial pressures.

You might also feel isolated in patient support groups where the average person is likely much older than you. And, when it comes to how others perceive lung cancer, you may struggle with not relating to the stereotype of the average lung cancer patient (which might be someone older and with a history of smoking).

All of these factors can impact your wellbeing, so please remember that you are not alone, and there is specialist support available for you.

Strategies for coping with lung cancer as a young person:

- Speak to your healthcare team who may be able to point you in the right direction or refer you to other departments for age-specific worries. This might include fertility planning and preservation, or support around career and education concerns
- Ask your cancer nurse specialist if there are any local support groups specifically for younger patients with lung cancer
- There are charities that support young adults with cancer specifically – such as Trekstock and Shine Cancer Support. Visit their websites for tailored advice on issues such as sex and relationships, coping at university, and much more

Mental health during treatment

Undergoing treatment for lung cancer can cause feelings of fear, anxiety, anger and confusion. Sleep disturbance can also be a common symptom among people living with lung cancer, and tiredness might add to these feelings.[8] There's also the stress of attending appointments and the emotional and physical exhaustion from the treatment itself.

You might feel frustrated at having to miss work and manage the side effects of treatment, or because you're having to rely on others. Sharing scan results with loved ones, or waiting to hear whether your treatment has been successful, can also place a significant emotional and mental strain on you.

Please remember that your healthcare team isn't just there to treat your lung cancer itself – they're there to support you mentally too. That's why it's important to speak up if you're struggling and ask for help.

It's also important to remember that everyone copes differently, and some coping habits can affect our health in the long run or benefit from additional support. This might include reaching out to a stop-smoking service, or community groups that support cessation of substance use (for example, alcohol or drugs), if you feel they could help you.

Strategies for looking after your mental health during treatment:

- There are lots of accessible and simple coping tools that can help you deal with feelings of anxiety. This might include journaling and writing down your worries to help process them, trying some relaxation or guided meditation apps, or engaging in gentle activities where breathing is a focus, such as yoga or pilates
- Charitable organisations might be able to help with some of the practical causes of stress around treatment – for instance, by providing transport to appointments
- Trying to focus on 'what is' rather than worrying about 'what if?' as our imaginations can fear the worst
- Reframing your mind to think about what matters to you rather than 'what's the matter with you' and focusing on things you're still able to do
- This 'Living well with lung cancer' handbook has specific information on coping with treatment at work and advice on childcare, that you may find useful
- If speaking to your family, friends or children about treatment is causing you stress and anxiety, you might find the 'conversation starters' on the next page helpful

Conversation starters for family and friends:

- “The thought of treatment is scaring me a bit. Would you mind helping me make a list of things that will help me feel comfortable?”
- “Here’s what my healthcare team have told me about my treatment plan – does this make sense to you?”
- “I’d really like to keep in touch when I’m having treatment. Your messages mean a lot”

Conversation starters for children:

- “You might not see me as much over the next few weeks as the doctors will need to see me in hospital to give me some medicine”
- “The doctors have taken some photos of my lungs to help understand if the medicine they’re giving me is making me better”
- “Even though the medicine I’m taking makes me feel tired, I’d still love to spend time with you. Is there anything you’d like to do?”

Anxiety and depression during remission

If you're in remission from lung cancer and have been given the all clear, you might feel as though you should be celebrating or experiencing joy and relief. However, studies have shown that people in remission for cancer can experience anxiety, depression, fear and distress for up to three years after treatment.[9]

There are lots of different reasons you might feel this way, including:

- Fears of the cancer coming back
- Loss of identity, routine and grief for a future life you might have imagined or planned
- Lack of medical safety net when you finish treatment and no longer see your healthcare team regularly
- The impact on your physical health which might mean you're no longer able to do activities that you could before treatment
- Feeling pressure to 'change back' into the person you were before cancer
- Survivor's guilt, especially if you know other people with lung cancer who have passed away

All of these feelings are valid, and it's okay and natural to feel this way. The coping mechanisms on the next page may be helpful, but if you're experiencing persistent low mood, or changes in sleep, appetite, interest, energy, or the ability to concentrate, please seek professional help from your doctor.

Strategies for coping during remission:

- The previously mentioned coping tools such as journaling, relaxation apps, and mindfulness techniques may be helpful – and you might find there are emotional benefits of maintaining these practices even after you've finished treatment
- Search online for support groups that might exist specifically for people who are in remission and take a look at the Roy Castle Lung Cancer Foundation online community forum
- If you're struggling with loss of identity, you might find it helpful to build new routines, such as:
  - Morning rituals, like taking a walk before breakfast
  - Joining a club or social group
  - Volunteering for a cancer charity, or supporting others who are going through lung cancer
- To help make things easier as you adjust to life post-treatment, ask friends and family for support. This might include help with childcare, food shopping, cooking or driving
- If you're experiencing survivor's guilt, you might like to keep a diary to help process these thoughts, and find ways to honour the memory of people who have died from lung cancer such as through fundraising or sponsored activities
- If you're struggling, ask your doctor or cancer nurse specialist about local community groups and charities, or for referral to counselling or other psychological treatment

Living with advanced lung cancer

Advanced lung cancer (stage 4), or metastatic cancer, means the cancer has spread to other parts of the body. Although it is not usually curable, advancements in treatments mean more people are living well and living longer with advanced lung cancer.[10]

Nevertheless, living with advanced lung cancer can bring significant mental health challenges. You might grieve for the life you thought you would get to live, or you and your loved ones may experience something called ‘anticipatory grief’, where you grieve for someone with a terminal illness while they’re still alive.[11]

There is also the potential loss of abilities, independence, or relationships as your cancer progresses.

This is a lot to cope with, but you aren’t alone – and help is available.

Strategies for coping with advanced lung cancer:

- If thinking about the future causes worry, try redefining it. You might like to set new goals for yourself, plan new milestones, and celebrate even the 'small wins' (things like finishing a meal if your appetite is low, completing a small household task, or spending an afternoon with a friend)
- You might find comfort in 'leaving a legacy' to help other people with lung cancer. This could include sharing insights with patient charities, or taking part in awareness-raising or fundraising activities
- Talking openly about your wishes and priorities for the future with your loved ones may help you to feel more in control of what's happening
- Take a look at charities like the Ruth Strauss Foundation which supports families facing an incurable cancer diagnosis, and Maggie's which offers courses and workshops to help people change the way they live with cancer
- As mentioned before, please ask your doctor or cancer nurse specialist for onward referral to mental health services if you're struggling to cope. This might include grief counselling, or treatment for post-traumatic stress disorder (PTSD)

If you're in immediate crisis or feel unable to cope, you can contact your GP, NHS 111, or Samaritans on 116 123 for urgent support.

Carer's mental health

While this handbook is aimed primarily at patients, you may wish to share this section with a loved one if you are worried about their mental health.

If you're caring for someone with lung cancer, you might be experiencing stress, anxiety and emotional fatigue. There's also the dual concern of wanting to manage your own wellbeing, while worrying about your loved one's condition and emotional state. Some people might not see themselves as an official 'carer', but they may still experience these feelings.

The impact of lung cancer on a person's entire family and support network should not be underestimated, and maintaining the mental wellbeing of loved ones is an important part of holistic care.

Strategies for coping with your mental health as a carer:

- Practice self-care — looking after yourself is just as important as looking after the person with lung cancer. This could include taking breaks from caring responsibilities, maintaining your own physical health, and continuing to pursue personal interests
- Try to share the emotional and physical burden of being a carer if you can. For instance, you could create a list of tasks that need doing and ask relatives to help with some of them. You might also like to schedule a weekly catchup with a friend where you can talk through how you're feeling
- There are support groups for carers and families within some patient organisations. The Roy Castle Lung Cancer Foundation, for example, offers one-to-one calls, helpline access, and tailored resources
- Please speak to your own healthcare team, such as your GP, if you start to feel overwhelmed, and if you're experiencing a crisis in your mental health, you can call the Samaritans helpline on 116 123

Living with lung cancer – whether you have the condition yourself or care for someone who has – can be challenging, but support is always available.

Glossary

Key term	Also known as...	Definition
Adjustment disorder		Emotional, psychological or behavioural symptoms in response to a stressor such as cancer, that impact daily life.[12]
Anticipatory grief	Grief before death Pre-death grief	Feelings of grief while someone is still alive. This can involve worrying about the future and how to cope without a loved one, and feelings of sadness and anger about the illness. The person who is ill can also experience this.[11]
Genetic mutation	Genomic alterations Genomic variants Genomic rearrangements Gene fusion	Specific changes that may occur in lung cancer cells, potentially disrupting normal cell function and that are somatic, which means that they are not inherited.[13]
Lymphoma	Lung lymphoma Primary pulmonary lymphoma	A type of cancer that affects the lymphatic system (part of the immune system), developing from white blood cells called lymphocytes. In rare cases, lymphoma can start in the lungs. This is called primary pulmonary lymphoma.[14]
Mesothelioma		A rare type of cancer that starts in the covering of the lung (the pleura).[5]

Glossary

Key term	Also known as...	Definition
Mindfulness	Grounding techniques Awareness	A technique for coping with anxiety, that involves intentionally focusing on what is happening in the present moment, rather than previous or future worries.
Neuroendocrine tumour	NET	A type of lung cancer that develops from neuroendocrine cells in the lung. These tumours can vary in how quickly they grow, and include small cell lung cancer and other less common subtypes.
Post-traumatic stress disorder	PTSD Post-traumatic stress symptoms (PTSS)	A mental health condition caused by experiencing a traumatic event. Some people who have lived with cancer/are in remission for cancer experience PTSD or symptoms of post-traumatic stress.[9]
Remission	No evidence of disease (NED)	A decrease in or disappearance of signs and symptoms of cancer, where cancer is no longer detected in the body.

Glossary

Key term	Also known as...	Definition
Sarcoma	Lung sarcoma	A rare type of cancer that develops in the supporting tissues of the body (bone, cartilage, tendons, fat and muscle).[15] Lung sarcomas have usually spread from a tumour located in another part of the body, but rarely, they can start in the lung.[16]
Scanxiety	Scan anxiety	A combination of the words 'scan' and 'anxiety'. This is the fear and anxiety people with cancer may experience before, during, and after medical scans, and while waiting for the results.
Stigma	Shame Disapproval	A sense of disgrace associated with a person or group that leads to disapproval, negative stereotypes, and discrimination. In lung cancer, there is often stigma associated with the condition and its link to smoking.[3]
Survivor's guilt		Feelings of distress or responsibility that occur when someone has survived lung cancer and others have not.

Questions to ask your healthcare team

It can be helpful to prepare a list of questions you'd like to ask your healthcare team before your appointments, as it's easy to forget them when the time comes. Here are some questions that may be useful:

- What support is available to help me manage my mental and emotional wellbeing during this time?
- Can we make a plan for what support I'll get to manage my mental health and what steps I should take?
- Who can I speak to if I'm struggling between appointments, or feeling anxious or low?
- What signs should I look out for that suggest I need more support with my mental health?
- How can I manage uncertainty while waiting for results or next steps in my care?
- What practical steps can I take to improve my mental well-being?
- What support is available to my family, carers, or loved ones?

Example conversation starters:

- "Can we discuss my mental health in this appointment? I have been experiencing feelings of depression since my diagnosis."
- "I am finding it difficult to sleep at night as I'm worrying about the future and it's impacting my daily life. What support is available to help me manage my anxiety?"
- "I feel overwhelmed and panicked before my appointments and tests. Can you share tips on how to manage this?"
- "I have experienced depression in the past and I'm worried it may come back. How can we monitor and adjust my care?"

Notes

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For more information and resources on lung cancer, visit the Talk Lung Cancer hub.

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