



Talk Lung Cancer...

A handbook for living well with lung cancer

Overview

If you are reading this, it is likely you, or someone you know, has been diagnosed with lung cancer. This handbook is intended to help you through your journey, providing general information, tips, and guidance on living better and coping with different aspects of your condition.

It's important to know that more people are living longer with lung cancer than ever before.¹ You shouldn't have to feel alone, and the support others can provide goes beyond your treatment plan. Your care team, charities, and patient support groups are on hand to provide practical, physical, and emotional support at each step of your treatment journey, and leaning on family, friends and loved ones can really help too.

This handbook summarises relevant information on living well with lung cancer, and signposts to additional resources should you wish to know more. You will also find a notes section at the end in which you can record any important information or questions you would like to ask your healthcare team after reading.

For more information about lung cancer – including the different types of lung cancer and treatment routes – we advise visiting the [NHS](#) or [Roy Castle Lung Cancer Foundation](#) websites.



Coping with a lung cancer diagnosis

A lung cancer diagnosis can be an unexpected, life-changing event. Everyone responds to it differently, but it is normal to feel a variety of different emotions, including shock, disbelief, confusion, sadness, anger, guilt and resignation. It is also normal for these emotions to feel overwhelming or uncontrollable, and difficult to cope with at first.^{2,3} What's important to remember is that ***there are people and organisations available to help you*** if needed.

Who can support me with my care journey?

Healthcare professionals

Your healthcare team is there to support you through your lung cancer diagnosis and the rest of your journey. The team will likely be multi-disciplinary, meaning it will include a number of professionals from different specialities, who will help you plan and support you with different aspects of your condition.

Your care team may also include:

- An **oncologist** (cancer doctor) who specialises in lung cancer treatments, including radiotherapy, chemotherapy, immunotherapy, and targeted treatments.
- A doctor who specialises in chest and breathing conditions, called a **pulmonologist**.
- A **specialist nurse** who has experience in caring for people with lung cancer.
- **Radiologists** who advise your oncologist on the results of your x-rays and scans.
- **Pathologists** who advise your oncologist on the type and extent of your cancer.
- A **surgeon** who carries out operations and who specialises in lung cancer.

Your healthcare team may also include specialists to help you manage other areas of your health whilst undergoing treatment, such as a dietitian, psychologist, physiotherapist, psychiatrist, counsellor and pharmacist.

Your friends, family or loved ones

The people closest to you can also play an important role within your lung cancer diagnosis and care journey. It is a good idea to discuss your condition with your friends, family or loved ones, explaining how you feel and suggesting ways that they could help you with daily activities.



Practical ways they could support you may include:⁴

- Helping you to get organised and keep track of appointments and paperwork.
- Driving and coming with you to tests, scans or other health appointments.
- Supporting you with eating balanced, nutritious meals.
- Joining or assisting you with keeping active.
- Providing practical support such as running errands for you that you would otherwise have to do yourself; for instance, picking up medicine that has been prescribed.
- Providing emotional support such as giving you space to open up about how you are feeling.

Charities and support groups

There are several organisations made up of experts in lung cancer care, who you can contact for advice and support. These include:

- [Roy Castle Lung Cancer Foundation](#)
- [Asthma + Lung UK](#)
- [Macmillan Cancer Support](#)

Work and lung cancer

How do I tell my employer?

Cancer will likely cause changes in many areas of your life, including your work life, if you're employed.

Remember that you do not have to tell your employer or colleagues that you have cancer, but it may help them to understand the support you might need, both emotionally and practically⁵

What might help is telling the colleagues you feel closest to first, as they may be able to help you plan how to tell others. Or, if the thought of speaking to multiple people about it is overwhelming, you can ask your manager to tell your colleagues about your diagnosis on your behalf.⁵

Changes to your job

While some people are able to carry on working while receiving treatment, you may need to take some time off, or perhaps make changes to your role such as reducing your hours or working remotely.

[Macmillian Cancer Support](#) has a range of resources to support you with work and cancer considerations, including your legal rights and questions around time off due to treatment.



You can also call Macmillan's Work Support Service – (+44) 08088 080000 – for advice on your options, including if you're self-employed or freelance. They'll also be able to give you advice about returning to work after your treatment.

Coping at work

If you carry on working during your lung cancer treatment, it might come as a welcome distraction, but it could take a toll on you mentally. Speak to your manager if you're struggling at any point, and make use of wellbeing services your company may offer, such as an employee assistance programme.

You may also be worried about the physical impact of your treatment, including side effects, changes to your appearance or the risk of infection. Speak to your HR team or manager, who will be equipped to provide help and potentially make reasonable adjustments. This might include things like adjusting your working hours to avoid travelling on public transport at peak times, or providing a quiet place to rest at work if you feel tired.



Financial and logistical support

Lung cancer can sometimes affect your finances.⁶ If you need to reduce or stop working because of your diagnosis, it might impact your financial situation. You may also experience increased travel costs due to appointments. This can potentially add stress and anxiety during an already difficult time – but you can access help and support.

Where to seek financial help

Your local council, charities or financial institutions may be able to support you financially during this time. They can offer advice on budgeting, or provide support if you need to apply for additional money. Understanding what resources are available to you can help you feel more at ease about your financial situation.

You may also be eligible to receive financial benefits from the Government, such as:

- Universal Credit
- Personal Independence Payment (PIP)
- Carer's Allowance (for somebody who cares for you)

Help is available

If you need to seek financial advice as a result of your diagnosis, contact [Citizens Advice](#), who'll be able to offer support.

Blue Badge applications

If your lung cancer symptoms are causing a significant impact on your mobility, you can apply for a Blue Badge. A Blue Badge will help you to park close to your destination, either as a passenger or driver.⁷

You can apply for a Blue Badge via the [Government website](#). When applying, you will need to send them a copy of the medical condition statement from your doctor or consultant – this is called a DS1500 report – which outlines your diagnosis, treatments and your symptoms.⁸

Childcare

If you're a parent, a lung cancer diagnosis may be especially hard to come to terms with emotionally, and it can bring practical worries around childcare too.



Asking your family, friends and loved ones for help – for instance, picking up your children from school – is always a good idea, but for people without that support network, further help is available.

Ask to speak to a social worker at the hospital, and your children's school or nursery may be able to provide flexible childcare support. You might also find it helpful to speak to a charity such as [Home Start](#), [Fruitfly Collective](#) and [Family and Childcare Trust](#), who are specially equipped to support parents with cancer.

Travelling to appointments

Arranging transport to hospital appointments can be difficult, particularly if you don't have a car or aren't served with reliable public transport links. Hospital car parking may also be expensive, so even if you drive, you may want to ask a friend or family member to take you and pick you up.⁹

However, if you're struggling to travel to appointments, or are worried about it, you may be able to access NHS patient transport services (PTS), which provides free transport to and from your appointment. It's not available in every area, so contact your GP to check.⁹

If PTS isn't available locally or you're ineligible, the Royal Voluntary Service offers [Community and Patient Transport](#), and may be able to arrange for a volunteer to take you.

Mental health and wellbeing

Living with lung cancer can feel like a winding road. Some days you may feel better than usual, and some days you may feel worse. While everyone's lung cancer journey will be different, ***looking after your mental health is always important.***

Coping with a lung cancer diagnosis and ongoing treatment can result in symptoms of depression, anxiety, stress, anger or worry, even in people who have not experienced these kinds of feelings before.¹⁶ Some people with lung cancer might also feel especially vulnerable due to concerns about being judged – for instance, from the stigma that can sometimes surround the connection between lung cancer and smoking.¹⁰

Mental health concerns are often complex and may require an array of support.¹⁰ You should never feel as if your care team are only there to assist you with your treatment. If you do feel depressed, or are struggling to cope with your diagnosis, they will be able to provide help and ensure you are always supported – whether it's directly through them or by connecting you with patient organisations.

It's really important to maintain an open dialogue with your healthcare team, as research has also shown that patients who work with their lung cancer team to better understand their illness and treatment options cope better with stress, anxiety and depression.¹⁰



Physical activity

In addition to your treatment, consider the positive effects that physical activity can have on both your condition and your overall health and mental wellbeing. Research shows that exercise is safe and may be beneficial for many people living with cancer.¹¹

Regular exercise can improve your quality of life, helping you feel physically stronger and less fatigued.¹¹ Staying active and undertaking light exercise has also been shown to help with tolerating, responding to and recovering from lung cancer treatments like chemotherapy, radiotherapy or surgery.¹²

It's important to seek your doctor's advice first to understand what level of exercise is appropriate for you.



What type of exercises are appropriate for people with lung cancer?

Starting a new exercise routine can feel overwhelming, particularly when coping with cancer. Below are some exercises that might be beneficial for you. These are only suggestions and you don't need to try all exercises – what's most important is finding some form of movement you enjoy doing.



Stretching¹²

Stretching increases circulation and can help your lungs to move more freely.

Upper body stretching can help if you are experiencing shortness of breath, as it increases your chest cavity (the area surrounded by your ribs and diaphragm) and lung capacity.

Stretching in general can also help combat the stress and anxiety of living with lung cancer.



Aerobic exercise¹²

Light aerobic exercise is typically recommended for people living with lung cancer. Your condition may make it harder to exercise in the same way you used to, so setting short-term, achievable goals can help you to maintain a good exercise routine.

Walking, dancing, swimming or any other activity which increases your heart rate are great examples of aerobic exercise. Improving your fitness will help strengthen the heart and improve your oxygen capacity.



Strength training¹²

Treatments like chemotherapy and radiation therapy can weaken your muscles. Strength training can help you counter this process by building your muscles, which can make everyday tasks easier.

Strength training can also help you improve your balance, posture and bone strength.

Exercises you could try include bicep curls, knee bends or heel raises. See this advice from [Roy Castle Lung Cancer Foundation](#) for a step-by-step tutorial on how to do these.

Remember...

Always speak to your doctor before starting a new physical exercise, and try not to push yourself too hard.

Be guided by your own body, and stop and seek advice from your healthcare team if you experience pain, dizziness or discomfort while exercising.



Breathing exercises

In addition to physical exercise, you may also benefit from breathing exercises. They can help improve your endurance, making it easier to complete daily activities and start exercising. One key exercise you can try is called diaphragmatic breathing:¹³

- 1 Lie down with a pillow under your head and under your knees. The pillow will help to ensure your body stays in a comfortable position.
- 2 Place one hand on the middle of your upper chest.
- 3 Place the other hand on your stomach, just under your ribcage but above the diaphragm.
- 4 To inhale, slowly breathe in through your nose, drawing the breath down towards the stomach. Your tummy should push upwards against your hand, but your chest should be still.
- 5 To exhale, tighten your abdominal muscles and let your stomach fall downward while breathing out through pursed lips. Again, your chest should stay still.
- 6 Practice this breathing exercise for five to 10 minutes at a time, around three to four times a day if possible.



Nutrition and eating well

After a lung cancer diagnosis, it can be challenging to maintain a healthy diet. It is common to experience weight loss during this time. In fact, around 60% of people with lung cancer have a loss of appetite or experience significant weight loss at the time of their diagnosis.¹⁴

Keeping track of your weight is important. Your doctor may want to find out what is causing your weight loss if you lose more than 5% of your normal weight over 6-12 months.¹⁴

You can keep track of your weight by weighing yourself regularly and noting down the results in a diary or notepad, or by inputting the results into an app on your mobile or digital device.

How to eat well with lung cancer

There is no right way of eating well, and it can vary from person to person, but maintaining your body weight and sticking to a balanced, healthy diet is important when living with lung cancer.

If you are experiencing a low appetite and are finding it difficult to maintain your body weight, you could try the following:¹⁵



Smaller meals

If a large plateful feels daunting, you may find it easier to eat three small meals a day with supplementary snacks and drinks.



Softer foods

Having cancer can make some foods feel harsh on your throat. Switching to soft or moist foods like soups, stews, or soft pasta can make mealtimes easier.



Avoid drinking before eating

Drinking large quantities of liquid may make you feel full and reduce your appetite. Avoiding drinks before mealtimes may help you to consume more food.

Speak to your healthcare professional if you are concerned or unsure about any of the above points, or wish to have more support on eating well with cancer.

Help and support

Where can I find people like me?

Support groups provide a safe space for people living with lung cancer to share advice and experiences with each other, and can be hugely beneficial. If you'd like to join a support group, your doctor or nurse will be able to help you find groups local to you.

You can also visit Roy Castle Lung Cancer Foundation's [website](#) to find out if the organisation runs a support group near you.



Questions for your care team

After receiving a lung cancer diagnosis, it's natural to have a lot of questions and you may wonder what the 'right' questions to ask are. Remember, it's important to ask the questions that come to mind, as these are likely the ones that are most important to you. Your healthcare professional is there to help and support you.

Below we have provided a list of questions that you might want to ask as a guide:

- What does a lung cancer diagnosis mean for me?
- What happens next after my diagnosis?
- What support services can my hospital offer me?
- What can I do to reduce feelings of stress and anxiety?
- What exercise would be best for me considering my diagnosis?
- What kind of foods should I be eating with my diagnosis?
- What should I do if I lose my appetite?
- How and where can I access mental health support should I need it?

Notes



A series of 20 horizontal grey lines providing a template for writing notes.

References

1. Cancer Research UK. World Cancer Day 2024: Improvements in cancer survival have slowed. Available at <https://news.cancerresearchuk.org/2024/02/02/world-cancer-day-2024>. Last accessed November 2024.
2. Roy Castle Lung Cancer Foundation. Coping with a lung cancer diagnosis. Available at <https://roycastle.org/about-lung-cancer/getting-diagnosed/coping-with-a-diagnosis>. Last accessed November 2024.
3. Macmillan Cancer Support. Just been diagnosed? Available at <https://www.macmillan.org.uk/cancer-information-and-support/diagnosis/just-been-diagnosed>. Last accessed November 2024.
4. Cancer Research UK. How to support someone with cancer. Available at <https://www.cancerresearchuk.org/about-cancer/coping/family-friends-caregivers/how-support-someone-with-cancer>. Last accessed November 2024.
5. Macmillan Cancer Support. Talking to your employer. Available at <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/work-and-cancer/talking-to-your-employer>. Last accessed November 2024.
6. Roy Castle Lung Cancer Foundation. Financial help. Available at <https://roycastle.org/about-lung-cancer/living-with-lung-cancer/financial-help>. Last accessed November 2024.
7. GOV.UK. The Blue Badge scheme: rights and responsibilities in England. Available at <https://www.gov.uk/government/publications/the-blue-badge-scheme-rights-and-responsibilities-in-england/the-blue-badge-scheme-rights-and-responsibilities-in-england>. Last accessed November 2024.
8. Roy Castle Lung Cancer Foundation. How to apply for a Blue Badge. Available at <https://roycastle.org/how-to-apply-for-a-blue-badge>. Last accessed November 2024.
9. NHS. How to organise transport to and from hospital. Available at <https://www.nhs.uk/nhs-services/hospitals/going-into-hospital/how-to-organise-transport-to-and-from-hospital>. Last accessed November 2024.
10. Roy Castle Lung Cancer Foundation. Protecting your mental health is vital when you have lung cancer. Available at <https://roycastle.org/protecting-your-mental-health-is-vital-when-you-have-lung-cancer>. Last accessed November 2024.
11. Cancer Research UK. Exercise guidelines for cancer patients. Available at <https://www.cancerresearchuk.org/about-cancer/coping/physically/exercise-guidelines>. Last accessed November 2024.
12. Roy Castle Lung Cancer Foundation. Getting active and exercising. Available at <https://roycastle.org/about-lung-cancer/living-with-lung-cancer/getting-active>. Last accessed November 2024.
13. Howell D. Enabling patients in effective self-management of breathlessness in lung cancer: the neglected pillar of personalized medicine. *Lung Cancer Manag*. 2021;10(4):LMT52
14. Cancer Research UK. Weight loss. Available at <https://www.cancerresearchuk.org/about-cancer/coping/physically/diet-problems/types/weight-loss>. Last accessed November 2024.
15. Roy Castle Lung Cancer Foundation. Eating well. Available at <https://roycastle.org/about-lung-cancer/living-with-lung-cancer/eating-well>. Last accessed November 2024.
16. Cancer Research UK. Mental health during and after cancer treatment. Available at <https://www.cancerresearchuk.org/about-cancer/coping/mental-health-cancer/during-and-after-cancer-treatment>. Last accessed November 2024.

Talk Lung Cancer has been developed by Janssen Pharmaceutica NV, with input from the following Patient Advocacy Groups and healthcare professionals.

