

*Managing your  
lung cancer diagnosis*



# Introduction

---

If you or someone you care for has just been diagnosed with lung cancer, then it's almost certain that you'll have a lot of questions.

We have produced this booklet in partnership with lung cancer experts and people affected by lung cancer to help you make positive informed choices about your care and treatment. Use this booklet along with information given to you by your healthcare team.

Remember that healthcare professionals are only too happy to answer your questions and help you with things that may be unclear or causing you concern.

If you still have questions and want to talk to someone, call our free and confidential **Ask the nurse** service on: **0800 358 7200** or email: [lungcancerhelp@roycastle.org](mailto:lungcancerhelp@roycastle.org)

You can also contact one of the many support organisations listed in our *Living with lung cancer* booklet. Order a copy by calling us on: **0333 323 7200** (option 2) or look at the contacts on our website: [www.roycastle.org/usefulcontacts](http://www.roycastle.org/usefulcontacts)

*We would like to thank and acknowledge Jane Holmes, who features on the front cover, for her support in helping us to produce this booklet.*

# Contents

---

<b>○ About your lungs and lung cancer</b>	<b>4</b>
How do my lungs work?	4
What is lung cancer?	5
Who gets lung cancer?	5
<b>○ Types of lung cancer</b>	<b>6</b>
Is it important to know what type of lung cancer I have?	7
Does lung cancer spread?	8
<b>○ What happens now?</b>	<b>11</b>
<b>○ Lung cancer tests</b>	<b>12</b>
Lung cancer staging	20
<b>○ Lung cancer health professional team</b>	<b>22</b>
Who might be involved in my treatment and care?	22
How do doctors decide on the best treatments to offer?	25
<b>○ Treating lung cancer</b>	<b>27</b>
How will I know what's best for me?	27
Treatment and care options	29
How will I cope with treatment?	35
What will life be like after treatment?	36
What if my lung cancer can't be cured?	37
What if I don't want to have anti-cancer treatment?	38
<b>○ Coping with your lung cancer diagnosis</b>	<b>40</b>
How will I adjust to having lung cancer?	43
What if I feel that I can't cope with my diagnosis?	44
How do I tell my children?	45
How will family members and friends cope with my diagnosis?	46
<b>○ Getting further support</b>	<b>48</b>
<b>○ Questions to ask your doctor or lung cancer nurse</b>	<b>49</b>

# About your lungs and lung cancer

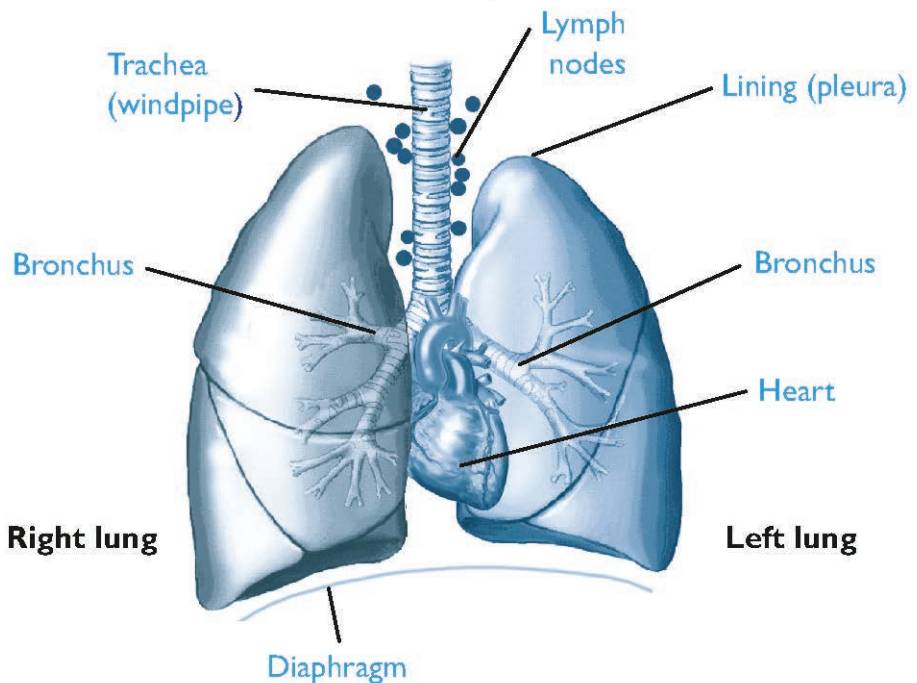
---

## How do my lungs work?

Everyone has two lungs. Each lung is divided into smaller sections called lobes – three on the right and two on the left. Your lungs are not the same size. The left lung has two lobes to allow space for the heart.

Every part of your body needs oxygen to function. You are able to breathe because your diaphragm muscle (shown below) and other muscles between your ribs work with your spine and ribs to increase the space in your chest to draw air in through your mouth and nose, and down your windpipe (*trachea*).

The trachea divides into the *left bronchus* and *right bronchus*, taking air into each lung. Like branches of a tree becoming twigs, these air passages continue dividing to become much smaller tubes (*bronchioles*). At the end of the smallest tubes are tiny air sacs called *alveoli*. These alveoli expand and “soak up” air as you breathe in.



---

The walls of the alveoli are very thin and allow oxygen to move from the air into the blood. They also allow carbon dioxide to move from the blood into the air in the lungs ready to be breathed out. The oxygenated blood is then carried from your lungs to the heart, which pumps the blood throughout the body, and then back to the lungs.

When you need more oxygen, such as when exercising or if frightened or stressed, it is quite normal to breathe faster and deeper and you can feel breathless. Your body is designed to do this.

### What is lung cancer?

Lung cancer is a term used to describe a growth of abnormal cells inside the lung. These cells reproduce at a much quicker rate than normal cells and do not die off like healthy cells.

Lung cancer is actually not one type of cancer. It is a range of different cancers that occur in the lungs. The abnormal cells grow to form a lump that is described by doctors as a *tumour*. Abnormal cells that first start growing in the lung are known as *primary lung cancer*.

### Who gets lung cancer?

Although around 10-15% of people who are diagnosed with lung cancer have never smoked, in the vast majority of cases, tobacco smoking is the main cause of lung cancer. Other possible causes or factors that increase the risk of developing it include:

- passive (secondhand) smoking
- exposure to asbestos, radon gas and some workplace chemicals
- a history of other lung diseases such as tuberculosis
- a family history of lung cancer
- cancer treatment for other types of cancer
- a lowered immune system

# Types of lung cancer

---

There are in fact quite a few different types of lung cancer, made up of different types of abnormal cells, but in general the disease is split into two main groups:

- non-small cell lung cancer (NSCLC)
- small cell lung cancer (SCLC)

## *Non-small cell lung cancer*

NSCLC makes up almost 9 out of 10 lung cancer cases in the UK, and has three common sub-types:

- *squamous cell cancer* – this can form in the larger, more central airways. It is often found near the centre of the lung in one of the main airways (the left or right bronchus). The number of people developing squamous cell lung cancer is going down in the UK.
- *adenocarcinoma (non-squamous)* – this is a little more common in women and more commonly seen in the outer parts of the lung. This type can produce excess mucus (fluid) in the lungs leading to a chronic cough.
- *large cell carcinoma (non-squamous)* – this type of lung cancer is generally more aggressive and often arises in the larger air passages. It has a tendency to spread outside the lung at an earlier stage.

Some of these cancers have genetic mutations. There are currently eight types of mutations (*targets*) that have available targeted treatment options including those referred to as ALK, EGFR, KRAS and NTRK.

---

## Small cell lung cancer

SCLC makes up around 1 in 10 lung cancer cases in the UK. It is made up of small round cells that form fleshy lumps and usually start in the larger airways. These cells reproduce and grow very quickly. It may spread to the lymph nodes and/or other organs in the body.

Small cell lung cancer is generally more responsive to chemotherapy treatment than other treatments, and radiotherapy may also be used. In rare cases, this type of lung cancer can be surgically removed.

Small cell lung cancer often reoccurs within a short space of time, so it is usual to attend regular check-ups to ensure any reoccurrence is found quickly.



Please see our *Understanding your small cell lung cancer* booklet for more information about this type of lung cancer. Order a copy by calling us free on **0333 323 7200** (option 2).

## Is it important to know the type of lung cancer I have?

Yes, it is. The most effective and appropriate treatment for you will vary depending on what type (*pathology*) of lung cancer you have, as different types of lung cancer respond best to different treatments.

For example, some patients' tumours test positive for one of the genetic mutations mentioned at the bottom of page 6. If they then receive a drug treatment matched to that mutation, they gain more benefit than from standard chemotherapy. Other tests check for levels of a cancer-cell protein known as PD-L1. These results can help doctors decide if immunotherapy may be a suitable treatment.

Doctors will do different tests to find this out, including taking small samples of the cancer (*biopsies*), though it can sometimes be difficult to reach the cancer to do this (see [Lung cancer tests](#) on page 12).

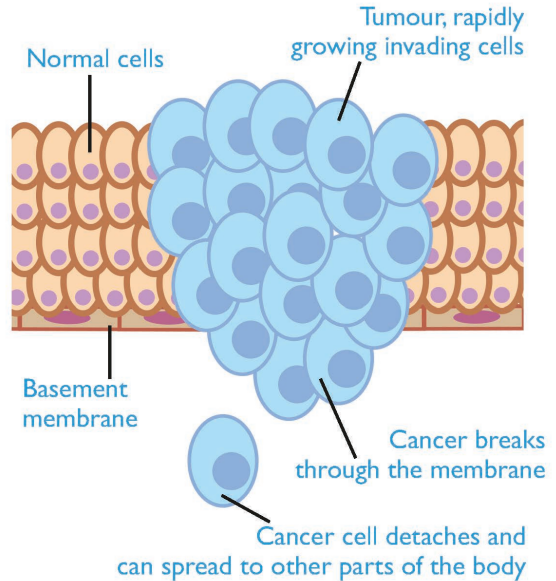
---

## Does lung cancer spread?

Although lung cancer often develops in a single area in the lung, it can also spread to other parts of the body. This is called *metastasis* or *metastatic disease*. Cancer cells can break from the primary tumour and be carried through the body's circulation in the blood or lymph.

It is usual for the lymph nodes near the centre of the chest to be affected first and then spread from there. The most common places of spread are the lymph nodes, bones (including the spine and pelvis), liver, kidneys, skin and the brain.

It is important to find out if any spread is present at diagnosis as this will help in deciding which treatment is best for you.



Symptoms that may be associated with lung cancer metastasis include:

- frequent headaches
- blurring of vision
- pain in the bones, for example, ribs, shoulder, arms or legs
- weakness or numbness in the legs
- sickness (especially in morning)
- lumps in the neck or on the skin

If you are worried about any symptoms, pain or changes after your diagnosis, talk to your hospital doctor or lung cancer nurse specialist. Many aches and pain and other symptoms may have nothing to do with your cancer and may be happening as a result of becoming less active.



---

## Can other cancers affect the lungs?

Yes, there are several, but most are rare.

### *Carcinoid tumours*

These are rare tumours of the lung that are generally less aggressive (spread more slowly) than other types. They are a form of tumour known as *neuroendocrine*.

The tumours develop from a particular type of cells in the lung (*neuroendocrine cells*). Many carcinoid tumours can be treated, and potentially cured, by surgery but some are more aggressive and can spread to other parts of the body and may require treatment with chemotherapy.

There are two types of lung carcinoid:

- *typical carcinoid tumour* – these grow slowly and only rarely spread beyond the lungs. Most lung carcinoids are typical carcinoids
- *atypical carcinoid tumour* – these grow faster and are more likely to spread to other organs. Seen under a microscope, they have more cells in the process of dividing and look like a fast growing tumour. They are less common than typical carcinoids.

Other tumours are so rare that current information is best given by your doctor or lung cancer nurse specialist:

- hamartoma
- bronchial gland tumours
- lymphoma
- pleural fibroma
- sarcoma

---

“ Learning all I could about the type of cancer my husband has, helped me understand things much better and grab a little bit of control in my life. ”

Gill

### Mesothelioma

Mesothelioma is a type of cancer that affects the outer surface of the lungs and some other organs, including the heart and stomach. It can also affect the outer linings of the lungs (*pleura*). However, we don't provide detailed information about it as it is *not a lung cancer*.

Developing mesothelioma is closely associated with a history of coming into contact with asbestos either through work or contact with a person exposed to it at work whose clothing, for example, may have carried asbestos fibres.



Your cancer doctor or cancer nurse specialist will be able to give you more information. You can also contact:

**Mesothelioma UK**

Helpline (Freephone): 0800 169 2409

Website: [www.mesothelioma.uk.com](http://www.mesothelioma.uk.com)

### Secondary cancer in the lung

Cancer that starts elsewhere in the body (*primary cancer*), such as in the bowel or breast, can spread, sometimes to the lungs. These would be classed as *secondary* bowel cancer, or *secondary* breast cancer, and not lung cancer. This means any chemotherapy treatment, for example, would generally be one that is used with the particular type of primary cancer, and not one used for lung cancer.

Your healthcare professional team would be specialists in the primary cancer that has spread to the lungs.

## What happens now?

---

Finding yourself sitting in front of a doctor telling you they know or strongly suspect you have lung cancer is likely to be a bolt out of the blue. It may be that you reached this point after noticing symptoms, visiting your GP and attending hospital for an X-ray. Around 51% of people are diagnosed after routine or urgent referral from their GP.

How you arrived at this point is probably less important to you right now than wanting to get information about what you can expect to happen next. Whether or not it's the first time you have had anything to do with hospitals and the healthcare system, it can seem a daunting prospect.

There are targets for how long you can expect to wait. For example, there is a 31-day wait target for the time between a decision to treat and the start of the treatment, and a 62-day target between the date of urgent referral for suspected cancer and the start of treatment. Your healthcare team will be able to tell you how quickly things are expected to progress in your hospital.

The process focusses on getting you the best care, and it may involve a series of procedures and medical tests, assessed by a range of healthcare professionals, leading to treatment options where that is appropriate for you and of your choosing.

While the assessment process and contacts with your medical team may appear a bit slow or spread out, there is a lot you can do to support yourself in the meantime. Speak to your team about what they recommend, such as exercising and other lifestyle choices, to help you be in the best shape you can be during this time.

The following pages may help you understand more about what is likely to be happening, with a section about helping you and those close to you cope and come to terms with your diagnosis.

## Lung cancer tests

---

There are many different tests and procedures that help doctors diagnose and treat lung cancer. Some are listed below, but each person's situation is different and your doctor will only use those most appropriate for you.

These descriptions will help you understand more about your lung cancer and how your medical team get the best possible information about your illness to give you the best options and outcomes.

Hearing that you are about to go through a series of tests that may or may not confirm that you have lung cancer can be shocking and frightening. It is normal to expect that it will all happen quickly and that the results will be available right away.

However, it is important to remember that, while some test procedures, such as biopsies, may be completed in just a few minutes, the process of examining the results may take a few days or even a couple of weeks. This can often add to people's anxiety and feel like you are being kept in the dark. It is worth being clear with your doctors at the outset about how long this is likely to be before your results are back.

If you do feel anxious, speak to your medical team or GP. There are also many options for you to try yourself to ease some of the tension such as listening to music, walking with a friend or going for a massage or aromatherapy session. Your local hospital may also offer complementary therapies.

Your hospital will also have more detailed information leaflets about these tests and procedures, how they carry them out, any benefits and possible risks involved, and any other safety concerns. If you have had a sedative, for example, you will need someone to pick you up afterwards as you won't be insured to drive.

---

“ Large numbers of tests are daunting.  
But they are also very important and provide essential  
information to allow the multi-disciplinary team (MDT)  
to decide the best treatments.

The more we know, the more we can do.”

Tom Newsom-Davis  
Consultant Medical Oncologist

**CT scans (computerised tomography)** use X-rays and a computer to create detailed, three-dimensional images of the inside of the body. They are carried out by trained operators called *radiographers*.

These scans can help doctors check your cancer’s position and possible spread to other organs, and if it is affecting any lymph nodes or blood vessels. Sometimes an injection of a contrast dye is given to help highlight some of the blood vessels around the heart and chest.

During the scan, you’ll usually lie on your back on a flat bed that passes into the CT scanner.

Simply put, the scanner is made up of a large rotating ring that moves around your body as you pass through it. It isn’t a tube so doesn’t surround your whole body at once, and you shouldn’t feel boxed in.

The procedure only lasts between 10 and 20 minutes. Afterwards you will be able to go home straight away, and eat, drink and get on with your day.



---

*MRI scans (magnetic resonance imaging)* are similar to CT scans, but these scanning machines use strong magnetic fields and radio waves instead of X-rays to produce their type of detailed three-dimensional images of the inside of the body. MRI scans are carried out by radiographers.

An MRI scanner is a short cylinder, open at both ends. You will lie on a motorised bed that is moved inside the scanner. When it is working, the scanner makes loud tapping noises. This is just parts of the machine being turned on and off. You'll either be given earplugs or headphones to wear so you can listen to music while the scan takes place. The scan can take up to an hour to complete.

This procedure is very safe and most people can have it, including pregnant women (though if you are pregnant you should let staff know).

Despite the magnets in the scanner, having something metallic in your body, such a metal plate, an artificial joint or a cochlear implant, doesn't necessarily mean you can't have an MRI scan, but you should make sure you tell the radiographer if you have. If you have a pacemaker, it usually means you will be unable to have a scan. However, some modern pacemakers are "MR conditional" meaning they don't cause as many issues as before. Take your pacemaker card or documentation to your appointments so your medical team can decide if you are able to have an MRI scan safely.

*PET scans (positron emission tomography)* give pictures showing where there is active cancer in the body. The scan is painless and quiet. PET scans are combined with a CT scan (PET-CT scan), and done together.

These are often used before lung cancer surgery and radical radiotherapy to make sure that curative treatment is possible. A PET scan is more accurate than a CT scan for this. This type of scan can also be used to investigate a suspected cancer if diagnosis has not been possible using other tests.

---

You will be given an injection of a special dye, called a *radiotracer*, about an hour before the scan. This dye highlights active cancer cells. Though it is a radioactive chemical, it is considered safe to use and any radiation that your body receives is very small. It quickly becomes less radioactive. Your body gets rid of the dye when you pass water so drinking plenty of fluid after the scan can help flush it out.

Because you'll be slightly radioactive during this time, you may be advised to avoid prolonged close contact with pregnant women, babies or young children for a few hours after your scan. You will be told at the time about any precautions you may need to take.

### **On the day of your scan**

Some people feel a bit anxious about getting a scan. If you do, let the radiographer know and they may be able to support you to feel calmer, give you a break, or perhaps arrange for you to have a sedative, or support you with some deep breathing exercises.

Also, if you wear any jewellery or clothes with metal in them, such as belts and zips, you'd need to take them off before the scan. This could include watches, necklaces, earrings, hearing aids, false teeth, bras and wigs (as some have metal parts). Sometimes you will be asked to undress and put on a hospital gown.

Make sure to tell the hospital if you have any allergies, kidney or blood clotting problems, and if you are taking medication, as radiographers may give you an injection of a dye for the scanner to give even clearer images.

The staff may want you to wait for up to an hour after the procedure to make sure you don't react to the dye.

---

**Ultrasound** is a painless scan that uses soundwaves to create an image of the inside of your body. It may be used to examine inside the kidneys, liver and lungs. It is frequently used to pinpoint fluid in the lung. Doctors can also use it to help them use a fine needle to get fluid samples from lymph nodes in the neck and near the collar bone (*clavicle*).

**Endobronchial ultrasounds (EBUS)** allow the doctor to look into your lungs (similar to bronchoscopies), but this time using an ultrasound scanner. A narrow flexible tube (an *endoscope*) with a tiny ultrasound machine on the end is inserted through your mouth into your airways. Before this procedure you will be given a sedative to make you sleepy.

Using the ultrasound to guide them, the doctor is able to identify the lymph nodes in the centre of the chest (*mediastinum*) or other areas of the lung that they want to test. A needle is then passed down the tube and through the wall of the airway into part of the lung to take samples of tissue for testing. This is known as **transbronchial needle aspiration (TBNA)**.

If the needle is passed through the wall of the airway into the lymph nodes to take a sample of lymph fluid, it is known as **fine needle aspiration (FNA)**. These samples are tested to see if the cancer has spread.

This procedure is not painful and taking the samples does not hurt but you may have a sore throat for a few days. It is usually performed as an outpatient meaning that most people go home the same day.

**Thoracoscopy** is a procedure that inserts a thin, flexible viewing tube (called a *thoracoscope*) through a small incision in the chest. The thoracoscope allows a doctor to look inside your chest at your lungs, the area between the lungs (*mediastinum*), and the membrane covering the lungs and lining the chest cavity (*pleura*). The doctor can also take tissue samples for testing.



---

**Aspiration of pleural effusion** is usually carried out to find out why there is fluid (*effusion*) around the lung, as this fluid may be causing symptoms such as cough, shortness of breath or chest pain. This thoracoscopy inserts the needle or tube into the space between the lung and chest wall to remove fluid that has accumulated around the lung. This space is called the *pleural space*. Ultrasound scans can help detect the fluid. This is usually a day case procedure, though you may need to stay in hospital for a few days if there is a lot of fluid to drain.

**Blood tests** can help find out about your general health and possible spread of lung cancer, and can check:

- how well your kidneys are working (for example, looking for higher than normal levels of creatinine, a substance muscles produce when they use energy to work, and that the kidneys filter and clear from your body)
- how well your liver is working (using liver function tests, or LFTs)
- your body's biochemical balance (for example, checking there is enough calcium and protein)
- any current infection or susceptibility to new infection (by looking at the number of white blood cells in your system)
- low circulating oxygen level caused by *anaemia* (a shortage of oxygen-carrying red blood cells called *haemoglobin*)
- if you bruise or bleed easily (by looking for cells in your blood called *platelets*).

**Bone scans** use a small amount of radioactive material (injected into a vein) to highlight any areas of the bones that have been affected by cancer, trauma, or inflammation. These are normally done on an outpatient basis.

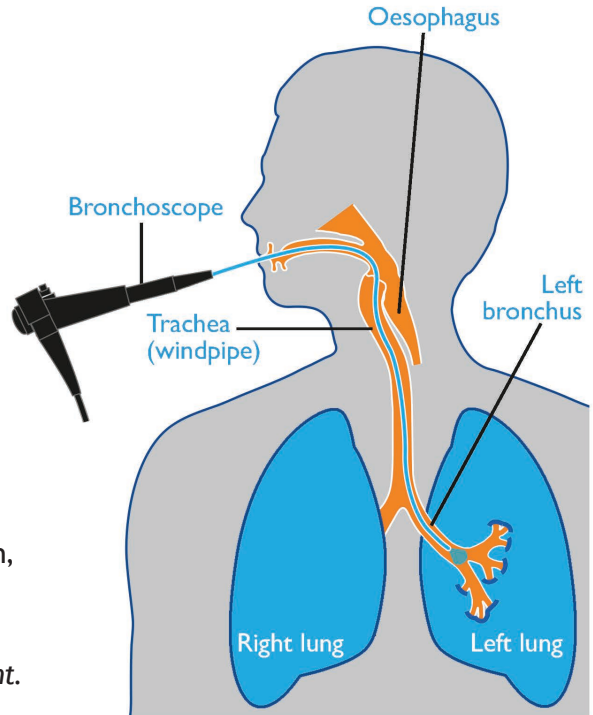
---

**Bronchoscopies** allow doctors to examine, photograph and take a tiny sample of tissue (*biopsy*) from inside your lungs and airways.

A narrow flexible tube with a tiny camera on the front will be inserted through your nose or mouth and down into your lungs.

Before this test, your throat will be sprayed to make it numb and a relaxing sedative will be given to you. If the doctors carry out a *rigid bronchoscopy*, you will receive a general anaesthetic.

If any abnormal areas are seen, a biopsy will be taken. If the tissue sample is found to be cancerous, it is called *malignant*. If not, it is called *benign*.



Some people find the procedure a bit uncomfortable, and it may leave you with a sore throat for a few days. A bronchoscopy is usually performed as a day-case procedure which means you will go home at the end of the day.

**Chest X-rays** take pictures of the body's internal structures and can sometimes show abnormalities such as inflammation, infection or growths. Many people have scarring on their lungs, without knowing about it, as a result of infections such as pneumonia or tuberculosis. This can show up on X-rays.

---

*CT guided biopsies* help doctors get very accurate tissue or fluid samples from inside your lungs and airways. After using a local anaesthetic to numb the skin on the front or back of the chest, a doctor will pass a thin, hollow needle through the chest wall and into the lung.

As they are doing this, they will watch a CT scan to guide the needle into the correct position to allow the biopsy to be taken. The biopsy can then be tested for cancer.

The procedure can sometimes be a bit uncomfortable, but it only takes a few minutes. You would normally get the test done as an outpatient, though after it, you will need to stay in hospital for a few hours for observation.

Occasionally during a lung biopsy like this, air can find its way into the space between the lung and the chest wall, causing the lung to collapse. This is called a *pneumothorax* (new-mo-thor-ax).

If it's a small pneumothorax, where a limited amount of air has entered, no treatment may be necessary and it will likely clear over a few days. If more air has entered resulting in a large pneumothorax, it may be treated by putting a drain (tube) into the chest to let the air escape.

*Lung function tests* check how well your lungs are working in terms of, for example, how much air you can breathe in and out, and how much oxygen your lungs can absorb. These tests may help decide if you are fit enough for surgery or radiotherapy, or if you have any ongoing lung conditions, such as emphysema. These simple tests usually involve blowing into a mouthpiece. Respiratory technicians may carry out these tests with you.

---

*Lung perfusion scans* produce a picture of blood flow to and around the lungs and can help assess how the cancer is affecting your lungs. A small amount of radioactive material (an *isotope*) is injected into a vein in your hand or arm.

You will then be positioned under a special camera that can detect the isotope in the blood vessels in your chest and lungs and a series of photographs are taken. The procedure lasts only about 20 minutes and so usually done during an outpatient appointment.

If you are a smoker, stopping or reducing how much you smoke, even now, can help you get better results on this test. This could mean your being able to have treatment that you could otherwise be too unwell to have according to the scan.

*Mediastinoscopy* is a surgical procedure for examining lymph nodes under the breastbone (*sternum*). For this test, you would need a general anaesthetic and a short stay in hospital. It may leave a small scar. Your doctor may want to do this procedure to make sure your cancer is suitable for surgery.

*Sputum (spit)* is a mixture of saliva and coughed-up mucus, often more noticeable if someone has an infection or other disease. Your hospital or GP may take a sample and send it for microscopic examination to help in your diagnosis.

---

## Lung cancer staging

Your medical team will use the results of all your tests to stage your lung cancer. Staging is a way of describing the size and any spread of cancer and is an important factor in deciding on the best treatment for you.

Staging for lung cancer may seem complicated, but your doctors will discuss how it applies to you and your cancer.

Doctors classify four stages of lung cancer with stage 1 being the earliest stage of cancer and stage 4 being the most advanced stage.

Doctors use a T(Tumour) N(Node) M (Mestastasis) system to group lung cancer into one of 4 stages. In this system, T (followed by a number 1 to 4) refers to the size of the tumour, N (followed by 0, 1, 2a, 2b, 3) refers to spread of the cancer to lymph nodes according to location and number of lymph nodes involved. M (followed by 0, 1a, 1b or 1c1 and 1c2) refers to any spread of the cancer to other parts of the body (metastasis).

The M category depends upon the number and site(s) of metastases.

The combination of numbers and letters means the extent of a person's lung cancer can then be generally grouped into one of the four stages. Your doctor will be able to break down each of these stages into sub groups.

*For example, a TNM system description of T3 N1 M0 would be stage 3A, relating to increasing progression of the cancer.*

This classification gives a clearer picture of the extent of the cancer and helps shared decisions about the treatment options.

\* Based on the International Association for the Study of Lung Cancer's 8th Edition of the TNM Classification for Lung Cancer ([www.iaslc.org](http://www.iaslc.org))

# Lung cancer health professional team

## Who might be involved in my treatment and care?

A team made up of various health professionals should be involved in your care. This is sometimes called a *multi-disciplinary team* or *MDT*. Your team will vary depending on where you are getting your treatment, but will most often include:

- a lung cancer nurse specialist
- a chest physician (respiratory consultant)
- an oncologist (cancer doctor) specialising in lung cancer
- a thoracic (chest) surgeon
- a radiologist
- a pathologist

There are many other professionals who may also be involved, though not necessarily part of the MDT. Knowing a little about what each person does will help you understand how they fit into the overall picture of your treatment and care.

*“The MDT is vital in ensuring treatment options are discussed by all the experts to make sure decisions are fair and fully agreed for each individual patient.”*

Lesley Holland  
Lung Cancer Nurse Specialist



Job title	Role
Anaesthetist	Doctors who carry out pre-operative assessments around fitness and suitability for surgery, and provide anaesthesia and post-operative care.
Chest/ respiratory physician	Doctors who specialise in chest problems. Performs tests such as bronchoscopies and biopsies (see <i>Lung cancer tests</i> on page 12) with a view to diagnosing lung cancer. Often the doctor who co-ordinates the first part of your cancer treatment or care.
Clinical psychologist	Helps with a wide variety of issues, such as anxiety, depression and relationship problems.
Dietitian	Provides expert advice to patients and carers about balanced diets and nutrition and adapting diets to maintain good weight for treatment.
District nurse	Visits you at home, to assess how you are and provide practical help such as changing wound dressings. Is also a contact between you and your GP.
Lung cancer nurse specialist (LCNS)	Your contact from diagnosis onwards, there to support you through the whole process, help you sort any problems and answer questions you may have.
Occupational therapist	Provides advice in adapting your lifestyle with a view to saving your energy whilst still being active. Can also advise on equipment to help you and alterations to your home if you need them. They may also help you with relaxation and fatigue management.
Oncologist (cancer doctor), medical and clinical	Doctors who provide expertise in the non-surgical treatment of cancer including chemotherapy, targeted therapies, radiotherapy and immunotherapy.
Palliative care doctor/nurse	Healthcare professionals who help manage symptoms, such as pain and fatigue, and support your psychological and spiritual needs.

Job title	Role
Pathologist	Doctors who specialise in examining biopsy samples and work out what type of lung cancer is present.
Physiotherapist	Helps you maintain or improve your mobility, strength and ability to exercise. Teaches you ways to manage your breathlessness and tiredness. You may also be able to work with a trained exercise specialist.
Radiologist	Doctors who specialise in carrying out examinations and interpreting medical images, such as X-rays, ultrasound scans, MRI and CT guided biopsies (see <i>Lung cancer tests</i> on page 12).
Social worker	Advises and helps with benefits/welfare rights, homecare, day care, child care and family relationships.
Therapy radiographer	Provides information about radiotherapy and administers treatments.
Thoracic surgeon (chest surgeon)	Doctors who specialise in performing surgery to the chest, including removal of part or whole lung.

*I first met my lung cancer nurse when I was diagnosed with lung cancer in 2009. Since then, she's always been there to support me and answer my questions.*

Hassan

There is space on page 50 for you to write down the contact information for the main people involved in your treatment and care.



---

## How do doctors decide on the best treatments to offer?

Once the multidisciplinary team (MDT) involved in your care have gathered all the information they need, including biopsy results, they will talk about your case.



When deciding what treatment and care options may be best to offer you, they will take into account several factors about your cancer, including:

- its size
- its type (small cell or non-small cell)
- where your cancer is
- if your cancer has spread

They will also consider your fitness and overall health to make sure your body can cope with it. For example, they will check:

Are your lungs working normally?

If there is damage to your lungs from other illnesses, such as chronic obstructive pulmonary disease (COPD), then some treatments may be ruled out as they could make your breathlessness worse.

Other health problems or illnesses

If you have other illnesses, this may increase the risk of some treatments, affecting the decision about which treatment is best for you.

Current symptoms

You may experience various symptoms such as general symptoms of not feeling well or specific symptoms related to your lungs or other parts of your body affected by the cancer.

Acceptability of side effects

Some treatments require a reasonable level of fitness to reduce the risk of side effects. If your general fitness is reduced, then these treatments may stop as they may become too harmful for you to cope with.

---

## National guidelines

There are national clinical guidelines for those involved in treating lung cancer. The guidelines are based on years of clinical evidence. They give a consistent structure to how doctors approach diagnosis, treatment and care for lung cancer.

They include, for example, the maximum length of time you will have to wait for treatment.

**You can find out more about national guidelines here:**



National Institute for Health and Care Excellence (NICE):  
*NICE Guideline NG122 – Lung cancer: diagnosis and management (2019)*

[www.nice.org.uk/guidance/ng122](http://www.nice.org.uk/guidance/ng122)

Scotland

Scottish Intercollegiate Guidelines Network (SIGN):  
*SIGN 137 – Management of lung cancer*

[www.sign.ac.uk/our-guidelines/  
management-of-lung-cancer](http://www.sign.ac.uk/our-guidelines/management-of-lung-cancer)

Macmillan Cancer Research is also a good resource for guidelines about treatment and care, including prehabilitation and rehabilitation. Search for 'guides' at: [www.macmillan.org.uk](http://www.macmillan.org.uk)

# Treating lung cancer

---

As with other cancers, lung cancer is most effectively treated when it is found before it has had a chance to grow and spread. However, because it may not cause any significant symptoms early on, lung cancer is most often found when it is more advanced.

Depending on what is happening with your lung cancer, treatments may focus on getting rid of it, reducing it or limiting its progress. While a cure is possible, it is not common as people's lung cancer is rarely found early enough in the UK.

How things go forward for you will depend on many factors, including:

- where in the lung the cancer is growing
- the kind or type of abnormality making the cancer cells
- the size of the cancer and how long it has been growing
- how fast the cancer is growing and if it has spread to other parts of your body
- your physical and emotional fitness

## How will I know what's best for me?

Your doctors will consider carefully the best options for you and talk them through with you. They may recommend one or more for you.

Because your medical condition and history are unique to you, your treatment will be too. Although your lung cancer may appear to be the same as someone else's, your treatment and care may be different.

You may also respond differently to treatment, and this may be down to several factors, such as having a health condition they don't have or a different level of fitness. This means something that works for them may not be as effective for you, even though you both may have the same type of lung cancer and similar symptoms.

---

Many treatments have side effects, and some can be difficult to deal with so you will need to weigh these up against the possible benefits. Ask your medical team about possible benefits and side effects of any treatments offered to you. You may get offered more than one type of treatment.

Treatments are developing all the time, and although the outcomes for many other cancers may be better, those for lung cancer are showing signs of significant improvement. In some cases, however, there may not be anything currently effective in controlling or reducing the cancer. In this situation, any treatments would focus on managing symptoms.

The decision to have treatment is entirely yours, and it won't start without your permission. Your medical team will talk to you in detail about their recommendations, but make sure you ask plenty of questions so you fully understand what is involved. Just because they give you treatment options doesn't mean you have to take them (see page 38). Working with your cancer team is the key to your being able to make the best decisions for you.

*Listen to all the options and keep an open mind.  
Don't make a snap decision – take time to think and talk  
things through with the people closest to you.*

*Don't be afraid to ask questions,  
especially if you don't understand something.  
If there is more than one treatment offered,  
don't worry about making a 'wrong decision' –  
what you think is best for you is the right treatment.*

Tom Newsom-Davis  
Consultant Medical Oncologist

## Treatment and care options

There are several treatment and care options available for lung cancer. However, not all of them may be appropriate for you.

### Prehabilitation

Prehabilitation brings together a range of services to support people diagnosed with lung cancer to be as fit and healthy as possible in the time leading up to and through any treatment.



There is growing evidence that, if people exercise more, eat well and generally look after their physical and emotional wellbeing, they can:

- cope better with their cancer and any symptoms
- increase the effectiveness of treatment
- improve their tolerance to treatment and recovery from it
- improve their overall wellbeing and quality of life

By taking these positive steps, people can also feel a bit more in control of what's happening to them. They would also make a positive difference to their health and wellbeing. This would improve their treatment options because they would be fitter.

Prehabilitation is being offered in more and more places across the UK as standard practice as part of a person's treatment. If it is offered to you, you will likely be assessed by health care professionals including a dietitian, a physiotherapist (or a specialist exercise professional) and a doctor who specialises in symptom management.

---

You will be asked about any symptoms, such as pain, coughing, and losing weight as well as how fit and active you are. They will then offer advice about exercise and eating well and may be able to put in place other support services. If you are a smoker, you will also receive support to help you stop.

They may be able to tell you about any recommended exercise classes or support meetings in your area that you can go along to, COVID-19 restrictions permitting, or connect to online. If your cancer team do not mention prehabilitation services to you, it may be worth asking about what is available for you elsewhere, locally or online.

### *Surgery*

Surgery is mainly used in the treatment of early-stage non-small cell lung cancer. Where the cancer hasn't spread, the surgeon can operate to remove the tumour along with surrounding lymph nodes in the chest.

Because small cell lung cancer can spread more quickly, surgery is not usually a treatment option.

### *Radiotherapy*

This cancer treatment uses high energy X-rays (*radiation*) to kill cancer cells in your body. It affects all cells, but affects rapidly dividing and growing cancer cells more. While normal cells can be damaged too, they can usually repair themselves. Cancer cells, on the other hand, do not.

### *Chemotherapy*

Chemotherapy drugs target rapidly dividing cells and kills them. This means they can be effective against cancer as its cells divide rapidly. Other cells in the body, such as hair follicles, and the lining of the mouth and bowel, also divide rapidly and react to the drugs, causing side effects. However, healthy cells are able to repair themselves while cancer cells do not recover.

---

## Targeted therapies

Targeted therapies only work for some people with particular types of non-small cell lung cancer. Cancer doctors will test some of your cancer cells (*biopsy*) to check for specific differences (*mutations*) of which there are several types (see page 6). Around 20% of NSCLC cases test positive for the two main types of mutation, EGFR (15%) and ALK (5%). Other mutations include ROS1, NTRK and KRAS.

Different targeted therapy drugs are effective against cancer cells that have these mutations. If tests show that your lung cancer has such a mutation, these drugs may work for you.

Also called biological therapies, targeted therapy drugs work by blocking the chemical processes in cells that make them divide and grow (unlike chemotherapy, which kills rapidly dividing cells).

## Immunotherapy

These drugs work with the body's immune system to help it attack cancer cells. They are used to treat some types of non-small cell lung cancer. Cancer doctors will test some of your cancer cells (*biopsy*) to check for specific differences that, if present, may mean some immunotherapy drugs will work for you.

The immune system helps your body protect itself from bacteria and viruses by producing substances known as antibodies. Normal, healthy cells have a way of staying safe from attack by the immune system.

However, some cancer cells can also avoid attack by looking like they are normal cells. The immune system leaves them alone and doesn't destroy them and so they can continue to multiply and grow.

Immunotherapy drugs stop these cancer cells being able to hide and the immune system can once again see and attack them.



### **Our information leaflets about treatments:**

- My lung surgery
- Radiotherapy for lung cancer
- Chemotherapy for lung cancer
- Targeted therapies for lung cancer
- Immunotherapy for lung cancer

You can get a copy of any of these by calling:  
**0333 323 7200** (option 2), or read them online at:  
[www.roycastle.org/how-we-help/  
lung-cancer-information](http://www.roycastle.org/how-we-help/lung-cancer-information)

### *Supportive and palliative care*

Supportive care is an umbrella term for a range of services that help you, your family and other carers cope with your lung cancer and any treatment. It should be given equal priority to other aspects of your care and begin even before your lung cancer has been confirmed.

This range of services includes:

- social support
- symptom control
- psychological support
- information giving
- self-help guidance

All health and social care professionals providing care and treatment have a responsibility for it, and you should expect open and sensitive communication from everyone involved.



---

Palliative care is an aspect of supportive care. This is a term used for the range of services available to you if your lung cancer is advanced and progressing, and a cure is not possible. This type of care aims to:

- provide relief from pain and other distressing symptoms
- support your psychological and spiritual needs
- help you to live as actively as possible, and help you, your family and others close to you adapt and cope over time
- work alongside treatments, such as chemotherapy and radiotherapy, intended to reduce your symptoms and slow your cancer's progression

As lung cancer is often diagnosed when already quite advanced, palliative care may be introduced from the start of any investigations or treatment. However, people can wrongly assume that when a person is being offered palliative care this is pretty much the same as being told they don't have very long to live.

Palliative care teams are usually made up of medical and nursing staff with special skills in pain control and symptom management. They work in a variety of settings including hospitals, the community, and in specialist units such as hospices.

If you are at home, they work closely with your GP and district nurse to make sure you get the best possible care and support. This will mean that you have easier access to a greater number of specialist services that may include day care, in-patient care and pain or breathlessness clinics.

End of life care is an important part of palliative care for people who are considered to be in the last year of life, but this timeframe can be difficult to predict. This care aims to help people live as well as possible and to die with dignity. It also refers to treatment during this time and can include additional support, such as help with legal matters. End of life care continues for as long as you or your loved ones need it.

---

## *Clinical trials*

Clinical trials are an essential part of medical research. They are a way of finding out if new treatments are better than current best practice, and may relate to any of the treatment options here.

On some clinical trials, your condition may be monitored more regularly than with standard care. This may include more blood tests, CT scans or other cancer tests. You may also spend more time with your doctor or nurse. This could mean that any changes in your health, whether related to the treatment you are having or not, are frequently picked up and acted upon earlier than if you were not in a trial.

It is important to keep in mind that the drug trial or research study on a new treatment is only carried out to find out if the new option is better than what is currently offered. It may be the same, or it may be worse. Drugs tested in trials may also not be available on the NHS after the trial ends, though people already getting the drug may continue to receive it for as long as it is effective.

Ask your cancer doctor about any clinical trials. Getting into a trial is often based on being able to meet some very specific criteria. Your cancer doctor will be able to tell you if you are eligible.

**If you would like to check what clinical trials are available, visit:**



Cancer Research UK  
[www.cancerresearchuk.org/about-cancer/  
find-a-clinical-trial](http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial)

National Institute for Health Research  
[www.bepartofresearch.nihr.ac.uk](http://www.bepartofresearch.nihr.ac.uk)

Clinical Net  
[www.clinicalnet.com](http://www.clinicalnet.com)

---

## How can I be sure I'm seeing the best doctor or getting offered the best treatment options?

This depends on which type of treatment is most appropriate for you. However, you should check that the doctor in charge of your care is a specialist in treating lung cancer. If they are not a thoracic surgeon or an oncologist, then you should ask why.

The choice of doctor leading your care and treatment options offered to you will have been discussed by the MDT and should be the best available to you given your test results. If you are unhappy with your treatment plan, speak to the doctor or your GP about your concerns and, if appropriate, ask for a second opinion.

## How will I cope with treatment?

Any serious illness can be hard to come to terms with, and going through treatment is just one of the challenges. For some, even the prospect of medical tests and hospital visits, even before any treatment starts, is enough to trigger worry and sleepless nights.

When something is new and uncertain, it is easy to feel anxious. Not knowing leaves plenty of opportunity for your imagination to create predictions that most likely will never happen.

The best way for many people to support themselves leading up to and through treatment is to ask lots of questions. Get the facts. Find out what things mean, how long things take, who will be involved, what you might expect and what activities you might be able to do. Ask about the likely benefits and risks of treatment you may be offered.

Your medical team are usually only too happy to help you understand, and help you take your time to take things on board. Remember that any treatment will only go ahead if you have understood what is involved and given your permission.

---

Many people can find it hard to take in new important information if feeling anxious or low. If you do struggle to concentrate when speaking to your medical team, make sure you get support as early as possible so you get the most from these discussions.

While many may find giving blood and having injections difficult, it is not uncommon for some people to have intense fears or phobias about medical procedures. Very often, these difficulties have a long history and have been around long before any diagnosis or treatment.

It is easy to suggest that you try to keep as relaxed as possible in the run up to each treatment. However, if you are finding it hard, perhaps feeling anxious or sick, or not sleeping through worry, then speak to your doctor, lung cancer nurse specialist or anyone else who is able to support you.

### **What will life be like after treatment?**

Many people look forward to the end of their treatment so they can feel like their life is getting back to normal. Others find this a difficult time as it means that you will have less contact with hospital staff and other patients.

You may feel confident about your cancer treatment and quite positive about planning and moving on with your life. Some people take time to think carefully about their priorities and you may want to do the same. Start by setting yourself small, achievable goals, and gradually build on them. Take each day as it comes, then each week, month and year.



---

Not everyone needs to stop working while receiving treatment, but that depends on your health and the treatment you are receiving. Targeted therapies, for example, are taken as a daily tablet at home and so won't disrupt your working routine.

Many people go back to work soon after treatment ends, whilst others may feel unable to return to the work they did before. Some people are able to arrange a more flexible working arrangement, such as fewer working hours or days, or agreeing a less physically or emotionally demanding workload.

If you are thinking about going back to work, speak to your cancer team. They can often support you when communicating with your workplace to make sure you are able to make the best possible transition back to work.

It is also normal to be concerned about your cancer returning. Many people who have been diagnosed and treated for cancer talk about how this concern may become part of everyday life.

Often, a new ache or pain may trigger worries that your cancer has come back. It is important to talk to your doctor about these concerns to be able to put your mind at ease or be supported through further checks.

### **What if my lung cancer can't be cured?**

Unfortunately, for lots of medical reasons, many people's lung cancer may never be cured. This news can be exceptionally difficult to hear. Some people become a bit preoccupied with the fact that, while there may appear to be so many available treatments, none will cure their lung cancer. It is common to go through strong feelings of blame, guilt and anger.

With improvements in treatment and care, lung cancer symptoms can be well managed. Even though your cancer can't be cured, you may well be able to live well with your condition and enjoy a good quality of life.

---

Getting a diagnosis of lung cancer that can't be cured is not automatically the same as being told you have a terminal illness. Your lung cancer may be incurable, but, with good treatment and ongoing care, you may lead a relatively normal life.

If you have had a diagnosis of incurable lung cancer and are finding it hard to accept, speak to your doctor or lung cancer nurse specialist.

There are also many other healthcare professionals able to help you, your family and others involved in your care and support through this potentially difficult time.

### **What if I don't want to have anti-cancer treatment?**

If your lung cancer is treatable, your doctors may offer, and even recommend, treatments because they see it will have benefits and be worthwhile. However, the decision to go ahead with it or not is entirely yours.

Having listened to your doctors' suggestions for treatments, the possible benefits they may bring, you may still decide you don't want a specific treatment, or you may choose not to have any anti-cancer treatment at all.

Weighing up potential benefits, such as managing symptoms, quality of life and perhaps living longer, against the potential impact of treatment schedules, medical procedures and possible side effects, you may still decide not to have any treatment.

People close to you, such as your family, loved ones or other carers, may have strong feelings about this and try to persuade you to change your mind. It is important though that you are clear in your own mind about what you are choosing to do.

Some people consider looking outside mainstream medicine for help.

---

There is a huge variety of complementary therapies advertised on the open market. Many are well known and proven to be helpful. However, there are also some therapies that are expensive and have doubtful or unproven benefits. Check the qualifications and any professional registration of any therapist you would like to use.

Be very wary of unusual (possibly illegal) and often costly therapies advertised in the media such as the internet or newspaper adverts. If you are in any doubt, speak to your GP or hospital team about whether it is safe for you and may be of any particular benefit.

Cancer Research UK ([www.cancerresearchuk.org](http://www.cancerresearchuk.org)) often has news articles about alternative treatments whose benefits are not clear, including cannabis oil. Trust information from such reputable sources and be wary of links shared on social networks claiming miracle cures.

Before taking any supplements, talk to your hospital pharmacy to make sure they are safe to take along with your other medications.

Whatever you do decide is best for you at the time, you can, of course, change your mind. If at a later date you reconsider your treatment options, speak to your cancer doctor. It is likely that doctors will need to reassess your lung cancer and consider the best next steps based on their findings.

Your treatment options may have changed and some previously available treatments may no longer be considered effective. On the other hand, because treatments are developing all the time, there may be new options for you to think about.

It may also be the case that as your lung cancer progresses, some anti-cancer treatment (perhaps chemotherapy or radiotherapy) may help with some symptoms, such as breathlessness or coughing. Speak to your doctor or lung cancer nurse at any time about treatment options as time goes on.

# Coping with your lung cancer diagnosis

---

Being diagnosed with lung cancer can be deeply distressing for you and those close to you. Hearing the news can make you feel like your world has been turned upside down and present you with unforeseen challenges.

You may react in different ways and feel different emotions. A cancer diagnosis can bring up fears about treatment in hospital, and sometimes wrongly, what it means for your future and the possibility of dying. Uncertainty about what is happening to you and what might happen can be very stressful.

You may feel differently as time passes after your diagnosis or during your treatment. Some people with lung cancer have talked about feelings of numbness, disbelief, shock, extreme sadness, anger and guilt, as well as helplessness and fear.



Many people find themselves looking for reasons and asking “why me?”. For some, a diagnosis of lung cancer may mean that life may never seem or be the same again.

In the early stages after diagnosis, people can often think of little else. Your sleep may be disturbed and you may feel very anxious.



---

These feelings are normal and not signs of being unable to cope. People commonly experience a range of strong and sometimes uncontrollable emotions after a diagnosis.

Particular situations trigger more anxiety for some people than for others. For example, going along to hospital appointments may bring up a lot of fear. Others worry more if they read about lung cancer in the newspaper or watch a programme on television where it is mentioned.

Thinking ahead to possible treatments and tests over the coming days and weeks may also increase your anxiety. You may notice a pattern to your feelings. If you notice how and when you feel them, this can be the first step in starting to manage them better.

Crying is a natural and reasonable reaction, so do allow yourself time to cry if you need to. It can help not to bottle up your fears and worries. Learning a relaxation technique can also be helpful as it can help you switch off your mind from worries. Releasing tension in your body can help calm your mind.

While some people do cry, others don't. Whatever way you handle this process is normal and right for you. Some people open up and share, others stay quiet and work things through in their own time. Don't feel guilty if you think you aren't "doing it right".

It can be all too easy to get caught up in just focusing on your illness and this can increase your worry. Some people find distraction a good strategy and reading, watching a film or going for a meal helps them cope.

If you struggle to do this on your own, tell your family and friends your plan and ask them to help. This may keep your mind on more positive things.

---

*Being diagnosed with cancer can be a very lonely experience. I didn't know anyone who had lung cancer. Having been through this, no one should go through this alone – ask questions, talk to people and take control of your life back.”*

*Brian*

For many people diagnosed with lung cancer there is an additional burden – coping with other people’s perception of the disease. Most people automatically assume that lung cancer patients smoke, despite the fact that about 15% of people diagnosed have never smoked.

So, both smokers and non-smokers can be on the receiving end of people’s (misguided) judgement that lung cancer is a self-inflicted disease, and is, to some extent, the person’s own fault.

While smokers may regret starting smoking when they were young, it is important to stress that nobody who smoked “caused” their cancer. The cause is the harmful chemicals produced by burning tobacco.

It is easy to overlook how addictive smoking is, and the vast efforts made by the tobacco industry to attract new smokers and keep others hooked.

Everyone with lung cancer deserves respect, hope and support and not judgement and exclusion. Being open to people who are positive, and avoiding those who are negative, will support you in handling your diagnosis better.

People with lung cancer and others affected by it sometimes become involved in promoting awareness of the disease as a way of coping with what is happening for them, and as a way of helping others who may find themselves in a similar situation.

---

For example, Roy Castle Lung Cancer Foundation has patient advocates who speak out about the disease, representing the charity at events, talking to the media and helping us to produce lung cancer information, such as the booklet you are reading now. This has been a positive experience for them too feeling involved in raising awareness about lung cancer.

It helps other people living with lung cancer to feel informed and supported. It can also attract more potential sources of funding for vital research, whether by encouraging people to do fundraising activities (swimming, running or abseiling, to name but a few), or by prompting the government or other corporate sponsors to increase their funding for research or healthcare. The stigma that affects people with lung cancer also affects the funding for research into the disease, and it lags behind most other cancers.

### **How will I adjust to having lung cancer?**

In the days and weeks following diagnosis, as you start to come to terms with the news, it is usual for these reactions to start to settle, although this varies from person to person. It is important that you should not be afraid to talk about your feelings and ask for support.

In some cases, people try to hide their emotions for fear of affecting others. However, trying to control how you feel can allow things to seem much worse.

At first, some people find it difficult to talk and need some time to sort things out in their own mind.

As you start to make sense of the news, you should begin to feel calmer. However, you may have even more questions, or feel angry. Everyone reacts differently. If you can talk about your thoughts and feelings with someone it may help. If you need support, find someone that you feel comfortable talking to, or you can write your thoughts down.

---

*I couldn't have got through my lung cancer treatment without my wife. Looking back, I was terrified at times but she helped me cope.*

Robert

### **What if I feel that I can't cope with my diagnosis?**

If your feelings and worries are interfering a lot with your day-to-day life and you are finding it difficult to cope, it may be worthwhile contacting your doctor or lung cancer nurse specialist.

There are other professionals who can help with problems you may be experiencing. A counsellor, for example, may be an understanding listener if you are anxious, troubled or distressed, and help you understand and come to terms with what is happening for you.

Having negative thoughts and beliefs about your health can be difficult. In some cases, this can lead to depression, anxiety and a loss of self-confidence. One way of dealing with this is to keep yourself involved in activities you enjoy and give you a sense of wellbeing.

*Focus on what you can do rather than what you can't. My motto is 'Keep on keeping on.' I now have that as a tattoo on my arm.*

Graham

Nevertheless, you may still find it difficult to manage your fears and worries. Remember, though, that it is understandable to be worried, but try not to let any concerns become too overwhelming or your imagination run riot. Focus your mind on things that are definite rather than on the "what ifs".

---

Consider ways that you may be able to take back some control of what is going on. Asking lots of questions and getting better understanding helps some. Others seek out people in a similar situation and talk about their experiences.

### How do I tell my children?

Talking to your children about this can be hard. It can seem natural to try to protect them from the news. Those closest to you may have a sense of things being different, even if they have not been told about the diagnosis. For many people, things they fear and don't understand can cause more worry than actually knowing what is happening.

*Positivity is important. But it's also okay to cry, feel scared, angry or any other way you may feel. Don't deny or pretend how you feel.*

Sandra

If you have young children and decide to tell them about your diagnosis and treatment, it is best to try to avoid too much medical jargon. Talk about what is happening to you using words they will easily understand.

It can be surprising how well some children do cope with the news. On the other hand, some may need a bit of extra time to take it all in and come to terms with things. Others may appear to be coping well but aren't really processing the situation. Everyone is different.

If they are finding it hard but don't say, you may get an idea about it if you notice changes in their behaviour. This can be a signal for someone to keep a closer eye on them and give them extra care and support. They may or may not come around to talking to you about it. They may also look for support from others and, whether you know about that or not, it is their choice to process the situation in the way they think best.

---

It can help to explain to children that it is normal for them, and for anyone, to experience some strong emotions at times like this. Let them know that it is ok to talk to you openly about anything worrying them.

Sometimes taking them along on a hospital visit and introducing them to staff can help reduce their fears.

There are some very useful books, written specifically for children, on the subject of illness in the family. A list of things for children to read is available from Macmillan Cancer Support ([www.macmillan.org.uk](http://www.macmillan.org.uk)), and includes their booklet *Talking to children and teenagers when an adult has cancer*.

If your child is of school age, it is a good idea to tell their teacher. This may help if there are any emotional or behavioural problems. Knowing what is happening means they can be sensitive to any changes in how your child behaves or how they feel. It may be useful to talk about it with your lung cancer nurse specialist or GP. They may have useful suggestions, or perhaps recommend referral to a social worker or child psychologist.

### **How will family members and friends cope my diagnosis?**

Dealing with a diagnosis of lung cancer involves not only coping with your own reactions but also the reactions of others around you. Some people may be very understanding, very helpful and know all the right things to say. Others may be over-protective, which at times can be very trying.

They may be very unsure about what to say to you and your family. It may be that some friends avoid you. Their lack of understanding can be distressing, but they may be worried about saying the wrong thing. Try and keep in touch with people who are able to support you. Being able to talk openly about your feelings and worries to them is important and it will really help you.

---

Remember, whatever worries or anxieties you are experiencing, your family and close friends are feeling them too. Some people find it helpful to talk to someone else who has been in a similar situation. Find out if there is a support group or cancer centre near you where others going through similar situation meet to talk and support each other.

*My family and friends have been incredibly supportive and I feel very lucky. I have remained upbeat and others seem to have taken the same approach.*

Jane



There are also online forums and helpline services you can use. Services are available to let you talk either as part of a group or on a one to one.

The forums can also be international. You can connect to people all over the world with a vast range of experiences, many similar to yours. Be aware, though, that many may not be moderated (where posts and information is checked and screened) by healthcare professionals or experts.

## Getting further support

---

### *Roy Castle Lung Cancer Foundation one-to-one services*

Our **Ask the nurse service** is a nurse-led helpline offering advice on all aspects of lung cancer including diagnosis and treatment. Please call our experienced team of nurses free on: **0800 358 7200** or email: **lungcancerhelp@roycastle.org**

Our **Keep in touch support service** offers confidential telephone contact for people with lung cancer and their carers. This service is primarily if you are socially isolated and would like some extra contact. You can have a fortnightly or monthly call over an agree timescale.

### *Roy Castle Lung Cancer Foundation group services*

We have a range of group support online, by telephone and face to face. Our **lung cancer support groups** and **information days** take place around the UK. These groups meet regularly when restrictions relating to COVID-19 permit and are organised by local lung cancer nurse specialists.

Our **Lung Cancer Connect** services offers online and phone programmes as well as video content to help you adjust to diagnosis, treatment and managing with lung cancer.

Our **online lung cancer community** lets you share your experience through blog posts and questions with other people affected by lung cancer. You can join free and anonymously at: **www.healthunlocked.com/lungcancer**



For information on our services please call our Information and Support Team on **0800 358 7200**, or email: **info@roycastle.org**



## Questions for your doctor or lung cancer nurse

---

Ask your cancer doctor or lung cancer nurse specialist these questions at your next visit to learn as much as you can about your lung cancer, treatment and care.

1. What type of lung cancer do I have?
2. What stage is my lung cancer? Has my lung cancer already spread, or is it likely to spread in the future?
3. What tests am I likely to have and what are they for?
4. How long do the results of the tests take to come through?
5. Is there anything that could stop me having treatment?
6. How is my lung cancer likely to affect me? Will I have more symptoms?
7. Will I be able to continue to go to work?
8. What options are available if I can't (or choose not to) have treatment?
9. Who will look after my care?
10. If I have treatment, what results can I expect?
11. Is there anything I can't do during treatment?
12. Can I go on holiday?
13. What other support is available?
14. What can I do to help myself?
15. What about clinical trials? Should I think about trying to get on one?

---

## Who are my main points of contact?

Name:

Job title:

Phone number:

Additional information:

Name:

Job title:

Phone number:

Additional information:

Name:

Job title:

Phone number:

Additional information:

# About our lung cancer information

---

We follow established quality standards and production principles to make our information trustworthy and easy to read. It is evidence based, following national clinical guidelines and best practice for managing lung cancer.

We believe information that is clear, accurate, evidence based, up to date and easy to use allows people to become better informed and more involved in their health and care.

Our information is written either by our information team or by lung cancer experts. We have a panel of lung cancer experts made up of doctors, nurse specialists and other health professionals involved in the treatment and care of people affected by lung cancer. These people help us on a voluntary basis. You can find out about our Expert Panel at [www.roycastle.org/expertpanel](http://www.roycastle.org/expertpanel)

This booklet has been published in partnership with Lung Cancer Nursing UK.



Our information is also reviewed by members of our Reader Panel (made up of people who have experience of lung cancer). This makes sure our lung cancer information meets their needs. You can find out about our Reader Panel at [www.roycastle.org/readerpanel](http://www.roycastle.org/readerpanel)

You can find references to sources of information within this booklet at [www.roycastle.org/evidence](http://www.roycastle.org/evidence)

If you have suggestions for new publications or additions or improvements to our existing range of booklets and factsheets, please let us know at [info@roycastle.org](mailto:info@roycastle.org)

Published: July 2023 Next review: August 2025

© Roy Castle Lung Cancer Foundation

Registered charity number England and Wales 1046854 - Scotland SC037596 - Isle of Man: 1277

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, including photocopying, recording or otherwise, without the prior permission of Roy Castle Lung Cancer Foundation.



ROY CASTLE  
**LUNG CANCER**  
FOUNDATION

Roy Castle Lung Cancer Foundation is the charity that gives help and hope to people affected by lung cancer. The charity has two aims – supporting people living with lung cancer and saving lives.

### **Supporting people living with lung cancer**

Working closely with lung cancer nurses, we provide information, run lung cancer support groups and offer telephone and online support.

### **Saving lives**

We fund lung cancer research, campaign for better treatment and care for people who have lung cancer, and raise awareness of the importance of early diagnosis.

Our lung cancer prevention work helps people to quit smoking and encourages young people not to start smoking.

---

### **Contact us**

For more information, call our Lung Cancer Information and Support Services:  
0333 323 7200 (**option 2**)  
or visit our website: [www.roycastle.org](http://www.roycastle.org)

#### **Head Office**

Cotton Exchange Building,  
Old Hall Street,  
Liverpool, L3 9LQ

**Email:** [foundation@roycastle.org](mailto:foundation@roycastle.org)

#### **Information and Support Services**

Suites 524-528 Baltic Chambers  
50 Wellington Street  
Glasgow, G2 6HJ

**Email:** [info@roycastle.org](mailto:info@roycastle.org)

---

## **Expect Better**

 [Roycastlelungcancer](https://www.facebook.com/Roycastlelungcancer)

 [@Roy\\_Castle\\_Lung](https://twitter.com/Roy_Castle_Lung)

For more of our information  
booklets and support,  
scan this QR code:

