



# Lung cancer

This booklet is for people who have been diagnosed with lung cancer, their friends, families and carers, and for people who want to know more about the condition. It explains what lung cancer is, what causes it, and how it is diagnosed. It provides information on symptoms and treatments, and what to expect if you are referred to a lung cancer clinic. You can also find information on financial help and emotional support.

## What is lung cancer?

Your body is made up of many different types of cells, and tightly controls the production of new cells when they are needed. Cancer develops when certain cells escape from your body's control and start to change. These abnormal cells, also called cancer cells, then start to increase and grow to form a lump. This is called a tumour.

Tumours can be benign or malignant:

- Malignant tumours are what we know as 'cancer' – they might grow quickly and can spread around the body to other organs.
- Benign tumours usually grow very slowly, if at all, and do not spread. However, they can make people ill by pressing on important parts of the body.

Most lung cancers develop in the airways that carry air in and out of your lungs, but they can also start in the lung tissue itself. If the cancer starts in your lung, it is called primary lung cancer. If it has started in another part of your body and spread to affect your lung, it is called secondary lung cancer.

There are many different types of lung cancer. The two main types are:

- Small cell lung cancer (SCLC). About 15 per cent of lung cancer cases are SCLC. Small cell lung cancer grows quickly and is often at an advanced stage when it is diagnosed.
- Non-small cell lung cancer (NSCLC). About 85 per cent of cases are NSCLC. NSCLC is actually a group of different types of cancer, including adenocarcinoma, squamous cell carcinoma and large cell carcinoma. These cancers grow more slowly and might be diagnosed at a stage where they can be removed by an operation.

## Who is at risk?

Anyone can develop lung cancer, but around 85 per cent of cases occur in people who smoke or who used to smoke. The risk of getting lung cancer increases with the total number of cigarettes you have smoked. If you stop smoking, the risk gets less over time. Breathing in other people's smoke over a long period of time can increase your risk of getting lung cancer. The condition usually affects people who are aged 60–80. Young people can develop lung cancer, but this is rare.

Non-smokers are more likely to develop one particular type of lung cancer – adenocarcinoma.

## What are the symptoms of lung cancer?

Cancer starts out as just one abnormal cell. It might take up to five years for it to multiply and grow big enough to be noticed. Often lung cancer will not cause any symptoms until the tumour becomes quite large. This means it might only be discovered when you have an X-ray or scan for a different problem. You will experience symptoms as your condition progresses. These might include:

- a cough that lasts more than three weeks
- feeling out of breath
- wheezing from one side of your chest (this might make it difficult to sleep on one side)
- blood in your mucus or phlegm
- pain
- weight loss

If you have these symptoms, you should see your doctor. However, these symptoms are also very common in people who do not have lung cancer. People with long-term lung disease might have many of these symptoms, but it's very important to tell your doctor if your usual symptoms change or become worse. Your doctor can arrange for tests to find out whether or not you have lung cancer.

If you have a tumour that has spread outside the lungs, the first symptom might not come from the chest at all. In this case, symptoms might include:

- jaundice (when the colour of your skin or eyes becomes yellow);
- bone pain or fracture;
- a skin lump; and
- nerve or brain damage. This might affect walking, talking, behaviour or memory.

### **I have symptoms that I'm worried about – what should I do?**

If you are worried about your symptoms you should talk to your GP, who might refer you for a chest X-ray. If you need an X-ray, discuss with your GP how you can make sure you get it quickly. After you've had your X-ray, you should receive your results within five working days.

If your symptoms are caused by lung cancer, a tumour can usually be detected on your chest X-ray. However, in up to 20 per cent of lung cancer cases, the X-ray looks normal, so you will need to take further tests to confirm if you have lung cancer or not. You should ask to be referred to a hospital lung cancer clinic if possible.

Remember that in many cases there will be another explanation for your symptoms other than cancer.

## How is lung cancer diagnosed?

If your doctor thinks you might have lung cancer, you will be referred to a special clinic at the hospital called the rapid access clinic or urgent cancer clinic. These services are set up to confirm if you have lung cancer or not, and provide specialist advice and treatment. Your hospital should aim to meet these targets:

- you should see a specialist at the hospital within two weeks of referral (if you live in England or Wales);
- you should be treated within 31 days of being diagnosed; and
- you should be treated within 62 days of referral.

In some cases, it can take longer than usual to diagnose or treat your condition. Waiting for tests and results can be very frustrating and upsetting. Remember that it is much more important to get the right treatment rather than getting treatment quickly.

### My first appointment with the specialist

At your first appointment you will usually see a doctor who specialises in lung diseases. The doctor will ask you lots of questions about your symptoms as well as about your medical history. He or she might also examine you. You can help by bringing an accurate list of any medicines you are taking to the appointment.

The doctor will explain the results of any tests you have done so far and advise on which further tests are needed. Most lung cancer clinics offer patients a CT scan before their first appointment with a specialist. If you have not already had this, then one will be organised for you (see below). Other tests might include blood samples, breathing tests and a bronchoscopy (see below). Usually, you will be offered the opportunity to meet a lung cancer nurse specialist. This nurse is there to help to arrange your tests, and provide you with further information. They will also give you their contact details so you can get in touch if you have any questions or worries.

### CT scans

After a chest X-ray, a CT scan is the next key step to diagnose lung cancer. A CT scan is carried out using a special X-ray machine. It produces an image of a cross-section, or slice, of your body. You will pass through a doughnut-shaped scanner while lying on a flat bed. Unlike an MRI scan, where you're placed inside a tunnel, you shouldn't feel claustrophobic. You will be given an injection in your hand, and the machine will take pictures of your chest and stomach area. The injection contains iodine, so make sure you tell the hospital staff if you are allergic. The scan only takes a few minutes, but provides a much more detailed picture of your lung and other organs that cancer can spread to.

The CT scan gives your doctor much more reliable information about whether you have lung cancer or not. If the scan shows a small tumour, but your doctor is still unsure if this is lung cancer, you might need to have another scan after several months. This means he or she can keep an eye on how the tumour behaves. In some cases the tumour won't grow, and cancer can be ruled out. If the tumour does show signs of growth, it is much more likely that you have cancer and will need to have treatment. A gap of 4–6 months between scans allows enough time to show any growth, but doesn't let the tumour grow so much that treatment becomes more difficult.

If the scan confirms that you have lung cancer you will need to have more tests to find out which type of lung cancer you have and how advanced it is.

## **The multidisciplinary team**

The doctor and nurse you see at your first appointment are part of a team of health care professionals who specialise in diagnosing and treating lung cancer. This multidisciplinary team (MDT) also includes X-ray specialists called radiologists, cancer specialists called oncologists, and surgeons who meet every week to discuss your test results and plan your care.

## **Further tests**

If you are diagnosed with lung cancer, the team looking after you will want to answer the following questions:

- What is it? Is this definitely lung cancer and if so what type is it?
- Where is it? Is the tumour only in your lung or has it spread? This is known as the stage.
- What do we do about it? When you have the above information, what are your treatment options?

To confirm that you have lung cancer, and which type you have, your doctor might need to look inside your lungs. He or she might also remove some cells for testing. This is called a biopsy. There are several different types of biopsy but the most common techniques are a CT-guided lung biopsy and a bronchoscopy.

- With a CT-guided lung biopsy, a needle is inserted through the skin into the tumour using CT-scan images as a guide.
- If you have a bronchoscopy, a narrow tube is inserted through your nose or mouth, down into your lungs. The tube has a camera on the end so the doctor can see inside your lungs. Your doctor might flush some water through the tubing, to remove cells for laboratory tests. You might be sedated for this test and your throat will be numbed first with a local anaesthetic.

In both cases, you will be given a local anaesthetic to make the procedure as comfortable as possible, and your doctor will explain to you exactly what will happen.

The results of your biopsy should be available after five to seven days. Sometimes, further work to look for genetic mutations (see page 8) might take longer.

## **PET scans**

If the results from your CT scan show that you have cancer, you might need to have a PET scan to see if the cancer has spread to other areas.

PET scanners have a flat bed with a large, circular scanner at one end. Before having a PET scan, you will be injected with a slightly radioactive substance, which can be detected by the scanner. You will be asked to lie down on the table, which will slide into the PET scanner. The scan is painless and takes around 30–60 minutes to complete.

Depending on your symptoms and scan results, other tests might be necessary to find out what stage the cancer is at, such as a bone scan or brain scan.

In order to work out your treatment options, your medical team will need to understand more about your general health and fitness, as well as about the type of cancer you have. For example, because many people with cancer are elderly and have other illnesses, heart and lung function tests might be needed to decide if someone is fit for surgery.

One of the team looking after you will discuss the results of all your tests and decide what treatment option is best for you and what other options are available. In most cases, your doctor will need to know what type of tumour you have and how far it has spread before discussing your treatment options with you.

You can find out more about different types of treatment on page 6.

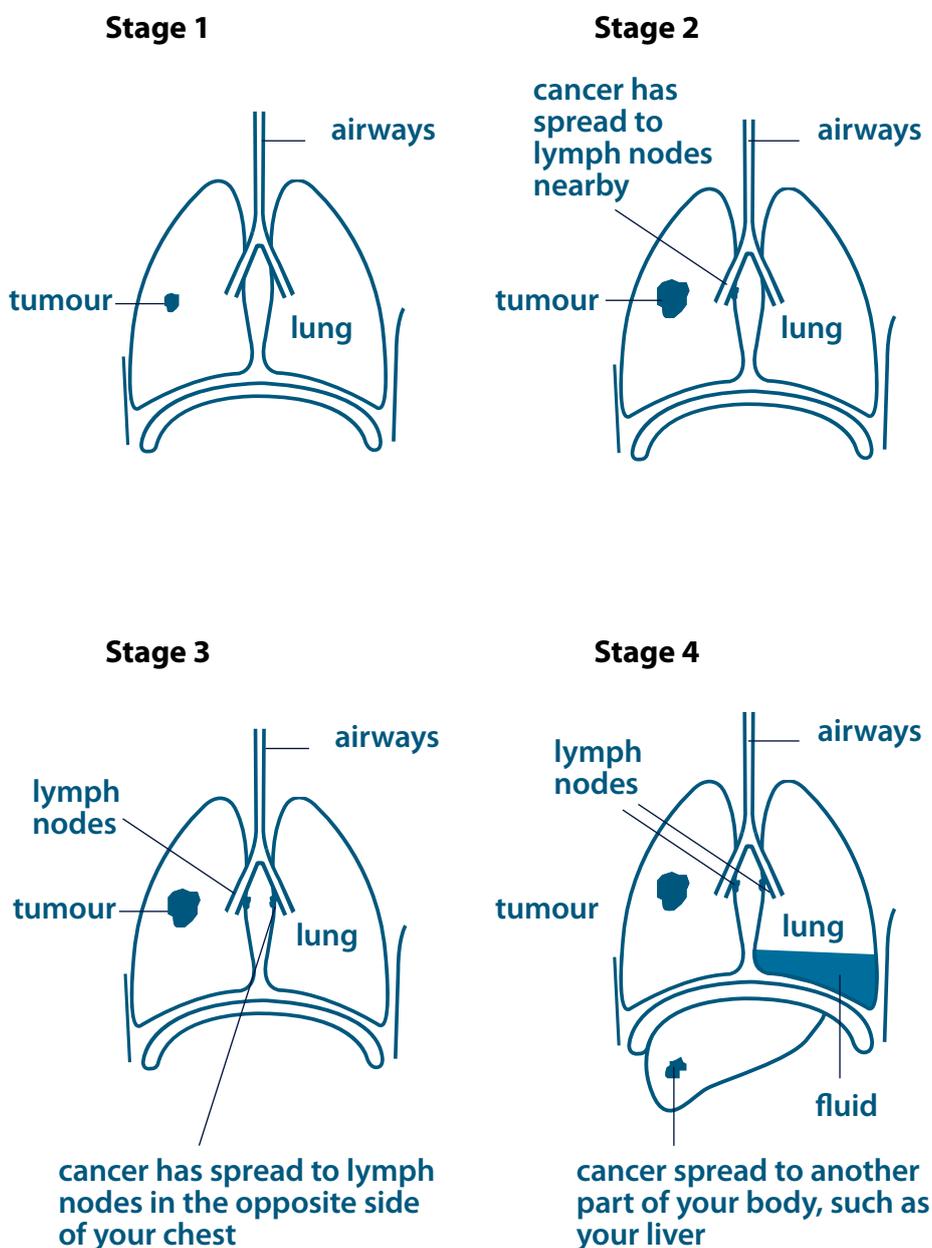
### What stage is your cancer at?

There are three factors used to work out where the cancer is in your body. This is called finding out what stage the cancer is at:

- T-stage – how large is the primary Tumour (where the cancer started) and what parts of your chest are affected?
- N-stage – has the cancer spread to any lymph glands (also called Nodes)?
- M-stage – has the cancer spread (or 'Metastasized') to other areas in your body?

Once the doctor knows these three factors, an overall stage will be decided, to show how large the cancer is and whether it has spread further around the body. Generally, cancer is divided into four stages:

- **Stage 1:** the cancer is small and has not spread to other parts of your body.
- **Stage 2:** the cancer is larger and might have spread to nearby lymph glands in your lung or into nearby tissues.
- **Stage 3:** the cancer has spread into lymph glands in the centre or the opposite side of your chest or has spread to the tissues in the middle of your chest.
- **Stage 4:** the cancer has spread outside your chest or caused a build-up of fluid in your chest. This is called a pleural effusion.



## Getting my results

Next, you will see your specialist doctor to discuss your test results and the treatment options that have been recommended. You will be offered the type of treatment that seems best for you, but you might want to talk to your family or a doctor you know well before you make a decision about treatment. The doctors and nurses will respect your views at every step.

You will probably want to ask lots of questions, such as:

- Will I be cured?
- What are the side-effects of treatment?
- Should I stop working?
- Can I still go on holiday?
- Am I going to die?

No-one will have all the answers, but the specialist doctor will answer your questions as honestly as possible. Your specialist nurse can give you additional support and extra information. If you have more questions, or just need to talk, you can call the BLF Helpline.

## What should I expect?

Sadly, only around nine per cent of people diagnosed with lung cancer will survive for five years or more. This is because the condition is often diagnosed at an advanced stage, and people with lung cancer are often elderly and have other health problems.

However, many people are cured of lung cancer, and even those that are not can still enjoy a longer and better quality of life with the right treatment. Your specialist doctor or nurse can talk to you about your outlook in more detail, but it is not always possible to be totally accurate.

## How is lung cancer treated?

In the past 10 years there has been a lot of progress made in the treatments available for people with lung cancer. Now people are usually given more than one treatment at a time, or might be given several courses of treatment. There are five main types of treatment for lung cancer:

- surgery
- chemotherapy
- radiotherapy
- targeted therapy
- palliative care

You might be invited to take part in a medical study, also called a clinical trial, to investigate new treatments. It's not an option for everyone but if you want to know more, ask your doctor or nurse. If you decide not to join a clinical trial, you will still receive the best possible care. You can also leave a clinical trial at any time if you change your mind.

## **Surgery**

Surgery is the preferred treatment for people with stage 1, 2 and some stage 3 lung cancers. There are several different types:

- Lobectomy: this operation will remove one section of the lung.
- Wedge resection or segmentectomy: this is when just a small piece of the lung is removed.
- Pneumonectomy: this is when the whole lung is removed.

Your doctor will consider your general fitness and whether you have any other medical conditions when deciding if you are suitable for surgery. Most operations are now carried out using keyhole surgery. This means the surgeon can operate without having to make a large cut or incision. Sometimes a large cut will be needed and it will take longer for you to recover.

Surgery is the treatment most likely to cure lung cancer, but there can be risks involved. Your specialist doctor will be able to talk to you about these risks in more detail.

It is important to understand that even if your operation seems to have been successful, there is still a risk that the cancer might come back. Once you have recovered from your surgery, you might be offered treatment with chemotherapy (see below) to reduce the risk of the cancer coming back.

## **Chemotherapy**

Chemotherapy means using medications to destroy cancer cells. If you have chemotherapy, the medications go straight into your blood stream to attack the cancer cells wherever they are, including outside the lung. But chemotherapy also affects normal cells, which means short-term side-effects are common. These might include hair loss, nausea and anaemia (when your body doesn't have enough iron). You might also have an increased risk of infection. Your doctor (an oncologist) will always try to reduce these side-effects as much as possible.

Chemotherapy medications are given through a drip (a device which slowly puts fluid into your vein) or through injections and tablets. You usually have two courses, or 'cycles', and then have another CT scan to see how you are responding to the treatment. If the chemotherapy is working, you might be given a course every three weeks, with four to six courses in total.

Chemotherapy is the preferred treatment if you have small cell lung cancer (SCLC). It is also given to patients with non-small cell lung cancer (NSCLC) before or after surgery to reduce the risk of the cancer returning. It is also used in patients with advanced NSCLC that cannot be cured, as it can improve symptoms and prolong life.

## **Radiotherapy**

Radiotherapy uses high-energy X-rays to destroy cancer cells. There are different types of radiotherapy treatment:

- A high dose of radiotherapy, called radical radiotherapy. This aims to cure the cancer if your tumour is small, but an operation is not possible. You might have several treatments over a few weeks. This treatment can cause short-term side-effects such as tiredness, dry throat or problems with swallowing. Your specialist nurse will give you advice about this and your medical team will see you regularly to check how you are coping with your treatment.
- A newer radiotherapy technique called stereotactic radiotherapy (SABR) uses scans and specialist equipment to precisely target radiotherapy to treat your tumour more accurately. It's only suitable for some people, and is usually given over a shorter time than standard radiotherapy (around three to eight treatments).
- A lower dose of radiotherapy, called palliative radiotherapy. This aims to improve symptoms such as cough, bleeding, pain or breathlessness. It only involves between one and five visits to the hospital and generally causes few side-effects.

## **Targeted therapies (or biological therapies)**

If you have an adenocarcinoma, a type of non-small cell lung cancer, the growth of the cancer cells might be caused by a genetic mutation. This is a permanent change that takes place within your DNA. Targeted therapy medications have been developed to stop these mutations, so the cancer cells stop growing. The most common type of mutation is known as EGFR and is present in about 10–15 per cent of adenocarcinoma cases.

Currently, targeted therapies are only suitable for people with advanced cancer. The cancer cells taken from your lung biopsy might be tested to see if a mutation has developed. If so, you will be offered treatment with a targeted therapy.

Targeted therapies are given as a daily tablet. They don't have the side-effects that people experience with regular chemotherapy, although you might get a skin rash. Unfortunately, cancers often become resistant to targeted therapies after a period of time.

Researchers are currently testing other types of targeted therapies through clinical trials.

## **Palliative care**

Sadly, sometimes lung cancer can't be cured, but there are treatments available to help control your symptoms. If your cancer is diagnosed at an advanced stage, or the symptoms are making you feel unwell, you might decide with your doctors that you want to receive palliative treatment. This uses medicines or other treatments to control the symptoms you might be getting such as a cough, feeling out of breath, loss of appetite or feeling weak. The aim of palliative care is to improve the quality of your life so that you feel as well as possible.

Your specialist doctor might be able to refer you to a palliative care team who can visit you and your family at home. Some of these teams are linked to a local hospice, and can provide lots of additional help and support during your illness.

## **Taking care of your feelings**

Being diagnosed with lung cancer can be frightening and it's normal to feel overwhelmed.

You might feel shock, fear, disbelief, anger, loneliness or resentment. You might feel a mix of some or all of these emotions. Sometimes it can be hard to accept that you have cancer, and you might feel like you just want to be left alone.

It's also a difficult time for your friends and family, who might be experiencing many of the same emotions.

When you are ready, it is important that you feel able to talk about your feelings. You can talk to friends and family, and you can also talk with your specialist cancer nurse. She or he can also help you find more specialist support with a counsellor or psychologist. Some GP practices have a counsellor as part of their team. Your GP can also tell you if there are community-based cancer nurse specialists in your area.

The specialist nurses and advisors on our helpline are also available to answer your questions or if you just need someone to talk to.

## Financial support

If you have lung cancer, you might have to give up work or spend more money than usual on things such as transport to appointments or extra prescriptions. You might feel worried about how you and your family are going to manage financially. Most people with lung cancer are entitled to financial benefits. For further information and advice on this, call the BLF Helpline. You can also contact your local Citizens Advice Bureau, or speak to the welfare benefits office at your local council. You can find the contact details you need below.

## Further information

### Macmillan Cancer Support

Runs local support groups for people affected by cancer, as well as information and support centres across the UK. You can also call the helpline for free from Monday to Friday, 9am to 8pm.

**0808 808 00 00**

**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

### Cancer Research UK

For more information about lung cancer including clinical trials.

**0808 800 4040**

**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

### Roy Castle Lung Cancer Foundation

Runs lung cancer support groups across the UK and a free lung cancer helpline from Monday to Friday, 9am to 5pm.

**0333 323 7200**

**[www.roycastle.org](http://www.roycastle.org)**

### Disability Benefits helpline

Anyone with a disability can get advice on benefits from this government helpline from Monday to Friday, 8am to 6pm.

**0845 712 3456**

### Citizens Advice

Provides information about benefits, money problems, and many other topics including NHS care, housing, disability rights and help from social services. You can also find your local bureau in the telephone book or at [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

**Visit [www.adviceguide.org.uk](http://www.adviceguide.org.uk) for information and advice**

### GOV.UK

Read about benefits and money matters on the government's main website:

**[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)**

**Carers UK**

Call the helpline or visit the website for support and practical information.

**0808 808 7777**

**[www.carersuk.org](http://www.carersuk.org)**

**Carers Direct**

The NHS resource for carers. You'll find lots of information and advice on services, plus a free course to give you extra skills and confidence as a carer.

**0300 123 1053**

**[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)**

**Quit**

Quit offers help, advice and support by trained counsellors to all smokers who want to stop.

**0800 00 22 00**

**[www.quit.org.uk](http://www.quit.org.uk)**

**NHS Stop Smoking Service**

Visit the website for information and advice, and to locate the free NHS stop smoking service nearest you. Or you can phone the free helpline.

**0300 123 1044**

**[www.nhs.uk/smokefree](http://www.nhs.uk/smokefree)**

**Stop Smoking Wales**

Offers free, local support to quit smoking.

**0800 085 2219**

**[www.stopsmokingwales.com](http://www.stopsmokingwales.com)**

**Smokeline (Scotland)**

Scotland's national stop smoking helpline.

**0800 84 84 84**

**[www.canstopsmoking.com](http://www.canstopsmoking.com)**

**Want2Stop (Northern Ireland)**

Information and advice on stopping smoking.

**0808 812 8008**

**[www.want2stop.info](http://www.want2stop.info)**

# Glossary

## **Airways**

The tubes carrying air in and out of your lungs

## **Biopsy**

Examination of a piece of your lung, to find out if you have cancer, and which type you have

## **Bronchoscopy**

A telescope in a flexible narrow tube is passed through your nose into your lungs so that your doctor can look inside

## **Cancer**

A lump of cells, also called a tumour, that damages healthy tissue and can spread to other parts of your body

## **Chemotherapy**

A course of treatment with powerful medicines, that attack cancer cells

## **Chest X-ray**

A safe and painless procedure that uses X-rays (a type of radiation) to produce images of the inside of your chest

## **CT scan**

A scan that uses an X-ray machine to produce an image of a cross-section, or slice, of your body

## **Hospice**

A centre which specialises in caring for people with advanced disease

## **Malignant**

Another word for cancerous

## **Multidisciplinary team (MDT)**

A team of specialists who work together to provide the best treatment and care for you

## **Oncologist**

A cancer specialist who uses chemotherapy or radiotherapy

## **Palliative care**

Treatment to reduce symptoms and make quality of life better

## **PET scan**

PET scans are used to produce detailed three-dimensional images of the inside of your body

## **Radiologist**

A specialist in X-rays, who is able to understand CT scan pictures and perform some types of lung biopsy

## Radiotherapy

A high dose of X-rays from a machine that kills cancer cells; it is usually done with the person lying down, and is painless

## Sedated

You are given a tablet or injection to make you drowsy

## Staging

A term used to describe where the tumour is, how big it is, and whether it has spread outside the lung

The BLF has more information and publications about lung cancer and living with a lung condition. You might find these useful:

- Lung cancer leaflet
- Looking after someone with a lung condition booklet
- Going on holiday with a lung condition booklet
- Breathlessness leaflet

The information above is free and available in print and online. You can read and order the information at [www.blf.org.uk/lung-health](http://www.blf.org.uk/lung-health) or by calling the helpline.



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We value feedback on our information. To let us know your views, and for the most up to date version of this information and references, call the helpline or visit [www.blf.org.uk](http://www.blf.org.uk)



**Lung cancer**

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