WE ARE MACMILLAN. CANCER SUPPORT A practical guide to understanding cancer

UNDERSTANDING LUNG CANCER



About this booklet

This booklet is about cancer that starts in the lung. This is called primary lung cancer. We can send you separate information about cancer that starts in another part of the body and spreads to the lung, which is called secondary lung cancer.

We hope this booklet answers some of your questions and helps you deal with some of the feelings you may have. We've also listed other sources of support and information, which we hope you'll find useful. Turn to pages 113–120 for useful addresses, and helpful books and websites. You can use page 121 to write down any notes or questions for your doctor or nurse.

We can't advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

Throughout this booklet we've included quotes from people affected by lung cancer. Some are from the website **healthtalk.org** Others are from people who have shared their experiences with us by becoming a Cancer Voice – find out more at **macmillan.org.uk/cancervoices**

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help support you.



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THE LUNGS AND LUNG CANCER

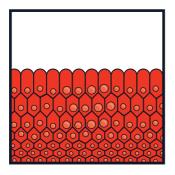
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What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour

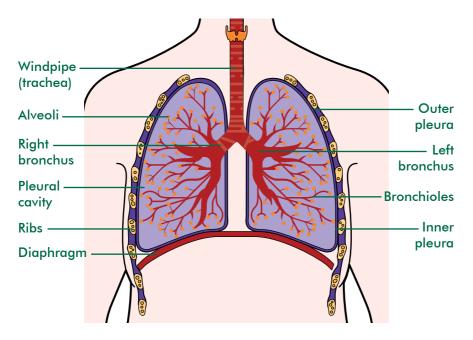
A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs. A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see page 10). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

We have a video on our website that explains how cancer develops. You can watch it at macmillan.org.uk/information-and-support

The lungs

The lungs are the parts of our body that we use to breathe. They supply oxygen to the organs and tissues of the body. The lungs are divided into areas called lobes. The right lung has three lobes and the left lung has two.

The lungs are covered by a lining called the pleura which has two layers. The inner layer covers the lungs. The outer layer lines the ribcage and a sheet of muscle called the diaphragm that separates the chest from the upper tummy (abdomen).



Structure of the lungs and pleura

The lungs are part of our respiratory (breathing) system, which includes the:

- nose and mouth
- windpipe (trachea)
- tubes that go to each lung (bronchus)
- lungs.

When we breathe in, air passes from our nose or mouth through to the windpipe (trachea). The trachea divides into two tubes (airways) that go to each lung. These tubes are called the right and left bronchus.

Air passes through each bronchus and into the lungs through smaller tubes called bronchioles. At the end of the bronchioles, there are tiny air sacs called alveoli. This is where oxygen from the air we've breathed in (inhaled) passes into the blood and is circulated around the body.

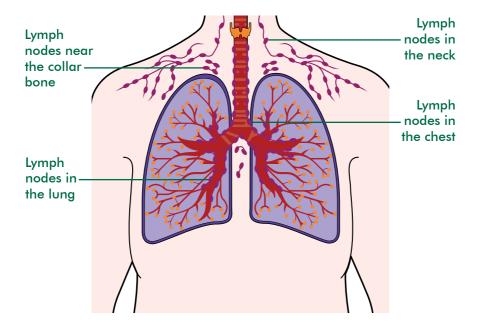
A waste gas called carbon dioxide passes from the blood into the air sacs (alveoli). We get rid of carbon dioxide when we breathe out (exhale).

The lymphatic system

The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body. Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection.

Sometimes, cancer can spread through the lymphatic system. If the cancer cells spread outside the lungs, they are most likely to go to lymph nodes in the chest.

Lymph nodes close to the lungs



Risk factors and causes

Lung cancer is the second most common cancer diagnosed in the UK. About 43,500 people are diagnosed with it each year.

Smoking is the cause of most lung cancers. There are also other risk factors that can increase the chances of developing lung cancer.

Having a particular risk factor doesn't mean you will definitely get cancer. And sometimes people without any known risk factors can develop cancer.

Smoking

Smoking tobacco is the cause of most lung cancers and the biggest risk factor.

The more you smoke (this includes cigarettes, cigars and pipes), the greater your risk. Around 90% of people (9 out of 10) who get lung cancer are smokers or ex-smokers. Starting smoking at a young age means the risk is higher.

Because more men used to smoke than women, lung cancer is still more common in men. But the number of men with lung cancer in the UK has fallen, while in women the number has increased due to more women smoking.

People who do not smoke can also develop lung cancer, but their risk is much lower. About 10–15% of people (around 1 in 10) who get lung cancer have never have smoked.

Ratio of smokers to non-smokers who develop lung cancer



When people stop smoking, their risk of lung cancer falls quickly. After about 15 years it's almost the same as a non-smoker.

Passive smoking

Breathing in other people's cigarette smoke (passive smoking) can slightly increase the risk of lung cancer. But it's still much lower than if you smoke yourself.

Age

Lung cancer is more common in older people. About 80% of lung cancers (8 in 10) are diagnosed in people over 60. It's rare in people under 40.

Radon gas

In certain parts of the UK, a natural gas called radon can pass from the soil into the foundations of buildings. Exposure to high levels of radon can increase the risk of developing lung cancer, but particularly if you smoke as well.

Asbestos

People who have been in prolonged or close contact with asbestos, previously used in building industries, have a higher risk of lung cancer. The risk is greater if they smoke.

Exposure to asbestos also increases the risk of mesothelioma, a cancer of the membranes that cover the lungs (the pleura, see page 8). If you have worked with asbestos and have lung cancer or mesothelioma, you may be able to claim compensation.

Our booklet **Understanding mesothelioma** has more information on making a claim. You can also talk to your cancer specialist or one of the organisations listed on pages 113–115 for advice.

Previous cancer treatment

People who have had radiotherapy to the chest to treat lymphoma or testicular cancer that has spread have a slightly increased risk of lung cancer. The risk is greater if they smoke.

But for these people, the risk of developing lung cancer is far outweighed by the benefits of their cancer treatment.

Lowered immunity

Having a lowered immunity as a result of illness or treatment can increase the risk of lung cancer. People with HIV and AIDS have a lowered immune system and also people who take drugs called immunosuppressants after an organ transplant.

Family risk

People with a close relative who had lung cancer may have a slightly increased risk.

If you're concerned about a family history of lung cancer, you may find it helpful to read our leaflet **Are you worried about cancer?** You can also talk to your GP.

Other causes

Contact with certain chemicals and substances, usually through work, can rarely cause lung cancer.

Recent research has shown that air pollution can cause lung cancer. But it's difficult to know the risk for individuals as it depends on the air quality where they live and how much pollution they are exposed to. For most people the risk is very slight compared to smoking, which is a major risk factor.

Lung cancer is not infectious and can't be passed on to other people.

Symptoms

The most common symptoms of lung cancer are:

- a cough for three weeks or more
- a change in a cough you've had for a long time
- a chest infection that doesn't get better, or repeated chest infections
- feeling breathless and wheezy for no reason
- coughing up blood
- chest or shoulder pain that doesn't get better
- a hoarse voice for three weeks or more.

Other possible symptoms are:

- losing weight for no obvious reason
- feeling extremely tired (fatigue)
- the ends of fingers change shape they may become larger or rounded (clubbing).

If you have any of these symptoms, it's important to have them checked by your GP. Some of these symptoms can be caused by other conditions or by smoking.

Lung cancer is occasionally diagnosed by chance when a person is having tests for another condition. In this situation, the cancer is more likely to be at an early stage.

Types of lung cancer

There are two main types of primary lung cancer. They behave in different ways and respond to treatment differently.

They are:

- non-small cell lung cancer (NSCLC), the most common type
- small cell lung cancer (SCLC), which makes up about 10% of lung cancers (1 in 10).

Non-small cell lung cancer

There are three main types:

- **Squamous cell carcinoma** is the most common type and develops in the cells that line the airways. It is usually caused by smoking.
- **Adenocarcinoma** develops from mucus-producing cells that line the airways. This type is becoming more common.
- Large cell carcinoma (sometimes called undifferentiated carcinoma) is named because of how the cancer cells look when examined under a microscope.

Small cell lung cancer

Small cell lung cancer (SCLC) also gets its name from how the cancer cells look when examined under a microscope. It's usually caused by smoking, and very rarely develops in someone who has never smoked. SCLC usually grows quickly and can spread quickly.

Mesothelioma

This is a cancer of the covering of the lungs (the pleura) and is less common. We have separate information about mesothelioma that we can send you.

Rarer types of lung cancer

Some people get other rarer types of lung cancer. Carcinoid tumour or soft tissue sarcomas are rare cancers that sometimes develop in the lungs.

We can send you information about carcinoid tumours and sarcomas.



DIAGNOSING LUNG CANCER

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How lung cancer is diagnosed

Most people are diagnosed after going to see their GP when they notice symptoms. Your GP will examine you and arrange for you to have tests. If your GP thinks your symptoms could be caused by lung cancer, they will arrange for you to have an urgent chest x-ray or possibly a CT scan (see the photo on the opposite page).

It may take a few days to get the results. If the x-ray shows anything abnormal, your GP will refer you to a chest specialist urgently. You should see the specialist within two weeks.

Sometimes GPs may make an urgent referral before getting the result of the chest x-ray.

At the hospital

The specialist will ask you about your general health and any previous medical problems before examining you. They will explain which tests you need.

You may also see a specialist nurse before or after you have your tests.

Your doctor may arrange for you to have one or more of the following tests to diagnose lung cancer.

Chest x-ray

If you haven't already had one, you will have a chest x-ray to check your lungs for anything that looks abnormal.

CT (computerised tomography) scan

Most people will have a CT scan. Depending on your symptoms, you may still have one even if your chest x-ray has not shown any signs of lung cancer.

A CT scan takes a series of x-rays, which build up a threedimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

Someone having a CT scan

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection. You'll probably be able to go home as soon as the scan is over.

CT scans can also be used to guide a biopsy, in which a small amount of tissue is taken to be examined under a microscope (see opposite page). You can usually have this as day surgery.

Sometimes a special type of CT scan called a PET/CT scan (see page 26) is used if there is only one small area in the lung that looks abnormal.

Bronchoscopy

A bronchoscopy is a test where a doctor or specially trained nurse looks at the insides of the airways (bronchus) and lungs (see page 8). A tube called a bronchoscope is used and the test is carried out under local anaesthetic.

During a bronchoscopy, the doctor or nurse may take samples of cells (biopsies) from the lung or airway. Before your bronchoscopy, you'll be asked not to eat or drink anything for a few hours. Just before the test, you may be given a mild sedative to help you relax and a medicine to stop you from coughing.

The nurse or doctor sprays a local anaesthetic on to the back of your throat to make it numb. They then gently pass the bronchoscope into your nose or mouth and down into the lung.

A bronchoscopy usually takes about 15 minutes, or longer if you are having biopsies taken. After it's over you should not eat or drink for at least an hour.

You can go home as soon as the sedation has worn off. You need someone to collect you from the hospital as you shouldn't drive for 24 hours because of the sedation. You may have a sore throat for a couple of days.

Lung biopsy

This test is done in the x-ray department, usually during a CT scan (see page 21) for guidance.

You'll be given a local anaesthetic first to numb the area. The doctor asks you to hold your breath for a few seconds, while they pass a thin needle through the skin and into the lung. They check the CT or x-ray picture to make sure the needle is in the right place.

The doctor removes a sample of cells from the tumour (biopsy). These are examined under a microscope for signs of cancer. The biopsy may be uncomfortable, but it only takes a few minutes.

After a lung biopsy, in a small number of people, air may get into the space between the layers that cover the lungs. This causes the lung to collapse (pneumothorax).

You may need to stay in hospital for a few hours after the biopsy to make sure there are no problems. Let your doctor or nurse know if you have any tightness or sharp pain in your chest or if you are breathless.

Fine needle aspiration from lymph node in the neck

Some people may have a sample of cells taken from the lymph nodes in their neck. First you have a local anaesthetic to numb the area. The doctor then inserts a very fine needle into the lymph node to withdraw a sample of cells. These are examined under a microscope for cancer cells. This test is done as an outpatient procedure, so you can go home the same day.

Further tests

If the first set of tests show you have lung cancer, your specialist will want to do some further tests. These are done to find out the size and position of the cancer and if it has spread outside the lung or to other parts of the body. This is called staging and the results will help you and your doctor decide on the best treatment.

Some tests may be repeated during and after your treatment.

Mediastinoscopy

This test allows the doctor to look at the area in the middle of your chest called the mediastinum and the nearby lymph nodes (see page 10). These are the first areas that lung cancer may spread to.

You have this test done under a general anaesthetic during a short stay in hospital.

The surgeon makes a small cut in the skin at the base of your neck and passes a tube like a telescope through the cut into your chest. The tube has a light and camera at the end and that magnifies the areas it looks at. The doctor can see any abnormal areas and take samples of the tissue and lymph nodes (biopsies) to check for cancer cells.

Thoracoscopy

This allows the doctor to look at the pleura (see page 8) and other structures around the lungs. You can have it done under a general anaesthetic. It can also be done with a local anaesthetic to numb the area and a sedative to make you drowsy. The surgeon makes a small cut in your chest wall and passes a tube called a thoracoscope (like the one we describe in a mediastinoscopy on the previous page) into your chest. Your doctor can then take a biopsy of the pleura.

Sometimes, doctors use a video camera to get a better view of the area surrounding the lung. This is called video-assisted thoracoscopy (see page 43).

Endobronchial ultrasound scan (EBUS)

This test may be done instead of a mediastinoscopy or thoracoscopy. Some people may have this test instead of a bronchoscopy or a CT scan and biopsy.

You can have it under a general anaesthetic, or using a mild sedative to help you to relax and feel drowsy.

The doctor passes a bronchoscope (see page 22), which has a small ultrasound probe on the end, down into your windpipe (trachea). An ultrasound uses sound waves that are converted into a picture by a computer. This test can show the size of a tumour and if any nearby lymph nodes are bigger than normal.

The doctor can also pass a needle along the bronchoscope to take biopsies from the lung or nearby lymph nodes.

Having a biopsy can be uncomfortable but it shouldn't be painful. Tell your doctor or nurse if you have any pain during or after the test so they can give you pain relief. It takes less than an hour and you can usually go home on the same day.

Endoscopic ultrasound (EUS)

This is similar to an EBUS and is also sometimes done as an earlier test for lung cancer. While you are under a general anaesthetic or mild sedation, the doctor will pass a small, flexible tube (endoscope) through your mouth and into your gullet (oesophagus). An ultrasound probe on the end of the endoscope creates pictures of the area around the heart and lungs. It can show if any of the lymph nodes in the centre of the chest are enlarged.

The doctor can pass a fine needle along the endoscope and take biopsies from the lymph nodes.

As with an EBUS, having a biopsy taken can be uncomfortable but shouldn't be painful. Let your doctor or nurse know if you have any pain during or after the procedure, as they can give you painkillers. This test takes less than an hour and you can usually go home on the same day.

PET/CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture (see page 21), and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET/CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one.

You can't eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30–90 minutes. You should be able to go home after the scan.

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet, so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you've ever worked with metal or in the metal industry, as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you'll be asked to remove any metal belongings, including jewellery.

Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Abdominal ultrasound scan

Ultrasound uses sound waves to look at the liver and other parts of the body in the upper abdomen. Once you are lying comfortably on your back, a gel is spread onto the area to be scanned. A small device that produces sound waves is passed over the area and the sound waves are converted into a picture by a computer. The test only takes a few minutes. An ultrasound scan is also sometimes used to look at the lymph nodes in the neck.

Bone scan

This test shows abnormal areas of bone. You have a small amount of a mildly radioactive substance injected into a vein. The level of radioactivity used in the scan is very small and doesn't cause any harm.

You wait for 2–3 hours after the injection before you have the scan, which may take an hour. Abnormal bone absorbs more radioactivity than normal bone and shows up on the scan pictures.

Lung function tests

If your treatment involves surgery (see pages 39–47) or radiotherapy (see pages 57–66) to try to get rid of the cancer, your doctor will arrange breathing or exercise tests for you. You have these to see how well your lungs are working.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 116–117 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Staging

The stage of a cancer describes its size and position, and if it has spread from where it started. Knowing the stage helps your doctors advise you on the best treatment.

Doctors use the same staging system for both non-small cell lung cancer and small cell lung cancer.

Your doctor may tell you the stage of the cancer using a number staging system, from 1–4. It looks at:

- the size of the tumour
- whether it has spread into nearby parts of the lung, or outside the lung
- whether it is in lymph nodes nearby, in the chest, or further away (see page 10)
- whether it has spread further outside the lung or to other parts of the body.

This staging also includes other things, such as whether the lung has partly or fully collapsed.

Most of the number stages are also sub-divided. We haven't included these here to try to keep it simple. Your doctor or nurse can explain more about your stage of lung cancer.

Stage 1

This is when the cancer is no bigger than 5cm. It is still inside the lung (localised) and not in any lymph nodes (see page 10).

This is early or localised lung cancer.

Stage 2

The cancer is no bigger than 7cm and may or may not have spread to nearby lymph nodes. Or, the cancer is bigger than 7cm and has not spread to the lymph nodes, but it is growing into other parts of the lung, or the airway, or to surrounding areas just outside the lung.

Stage 3

The cancer can be any size and has spread to lymph nodes. The cancer may also be growing into other parts of the lung, or the airway, or to surrounding areas outside the lung. The cancer may also have spread to tissues and structures further away from the lung. But it hasn't spread to other parts of the body.

Stage 2 and Stage 3 lung cancer are usually called locally advanced lung cancer.

Stage 4

The cancer can be any size, may have spread to lymph nodes and one of the following:

- The cancer has spread to the lung on the other side.
- There are cancer cells in fluid in the pleura or around the heart.
- The cancer has spread to another part of the body, such as the liver, bones or brain.

Stage 4 lung cancer is called metastatic or secondary lung cancer.

Small cell lung cancer

Doctors may divide small cell lung cancers into two stages:

- Limited disease the cancer cells can be seen in one lung and in nearby lymph nodes.
- **Extensive disease** the cancer has spread outside the lung, to the chest area or to other parts of the body.

Small cell lung cancers are usually treated as if they have spread, even if doctors can't see any evidence of this on your scans.

This is because the cancer can spread outside the lung quite early on. Some cancer cells are likely to have already spread through the blood or lymphatic system, but this may be too small to show up on scans.



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Treatment overview

Treatment for lung cancer can include surgery, chemotherapy, radiotherapy and targeted therapies. The treatment you have will depend on the stage and type of cancer. You may have a combination of treatments.

Non-small cell lung cancer (NSCLC) and small cell cancer (SCLC) are treated in different ways.

Surgery may be possible to remove NSCLC. Surgery is rarely used to treat SCLC.

Chemotherapy (anti-cancer drugs) is used in both types of lung cancer. If you have SCLC, chemotherapy is usually your main treatment. Chemotherapy can be given before or after surgery for NSCLC. Some people have chemotherapy at the same time as radiotherapy. This is called chemoradiation. Chemotherapy can also be used to control symptoms.

Radiotherapy treats cancer by using high-energy x-rays. For NSCLC, you can have it instead of surgery to try to cure an early cancer. It can be given after chemotherapy and sometimes along with it (chemoradiation) in both NSCLC and SCLC. Radiotherapy is also used to control symptoms when the cancer is more advanced or has spread to other parts of the body.

Targeted therapies (see pages 67–69) use drugs to stop the signals that encourage cancer cells to grow. They are usually used to treat advanced NSCLC.

Ablation treatments (see pages 70–74) that use heat (radiofrequency ablation) or laser light (photodynamic therapy) are sometimes used to treat very early stage lung cancers. Other tumour ablation treatments, such as laser, can be used to relieve breathlessness if the cancer is blocking an airway.

Your doctor and specialist nurse will involve you in treatment decisions so that your preferences are taken into account. They can also help you if you need to make decisions about treatment. Some people may have different treatments one after the other to keep the cancer under control. Newer treatments are also being developed. Your cancer doctor may talk to you about taking part in research, such as a clinical trial.

If the cancer has spread to other parts of the body, you can have treatments and drugs that can reduce your symptoms. This is sometimes called supportive care (palliative care). You can see a specialist doctor or nurse for expert help with your symptoms.

How treatment is planned

In most hospitals a team of specialists will plan the treatment they feel is best for your situation. This multidisciplinary team (MDT) will include:

- a surgeon (who specialises in lung cancer)
- an oncologist (a cancer doctor who specialises in radiotherapy, chemotherapy and targeted therapies)
- a doctor who is an expert in chest and breathing conditions
- a nurse specialist
- radiologists who help to analyse x-rays and scans
- pathologists who advise on the type and extent of the cancer.

The team may also include other healthcare professionals, such as a palliative care doctor or nurse who specialises in symptom control, dietitian, physiotherapist, occupational therapist (OT), psychologist or counsellor.

After the MDT meeting, your doctor and specialist nurse will talk to you about the best treatment plan for your situation. They will explain the benefits and disadvantages of different treatments.

If you smoke, your doctor may advise you to try to stop smoking. Giving up can have a positive effect on your treatment. Your GP should be able to offer different treatments to help you quit. Whether or not you stop should not affect the treatment plan your team offer you.

> Our booklet **Giving up smoking** has practical tips on how to stop smoking and stay stopped.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you. You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

The benefits and disadvantages of treatment

Many people feel anxious at the idea of having cancer treatments, particularly because of the side effects that can happen. However, these can usually be controlled with medicines. Treatment can be given for different reasons and the possible benefits will vary depending on your situation.

In people with early lung cancer, surgery or radiotherapy may be done with the aim of curing the cancer. When the cancer has spread outside the lung, you can have treatments to shrink the cancer and help you to live for longer. If the cancer is very advanced and has spread to other parts of the body, treatment may only be able to help control it and improve symptoms and quality of life. However, for some people, the treatment will have no effect on the cancer and they have the side effects without any of the benefit.

If you've been offered treatment that aims to cure the cancer, deciding whether to accept it may not be difficult. However, if a cure is not possible and the aim is to control the cancer for a time, it may be harder to decide whether to go ahead.

Making decisions in these circumstances is always difficult. You may need to discuss in detail with your doctor whether you wish to have treatment. If you decide not to have it, you will still be given supportive (palliative) care, with medicines to control any symptoms.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Surgery

Surgery for lung cancer involves removing the cancer and the nearby lymph nodes in the chest. Whether surgery is suitable depends on the type of lung cancer you have, its stage and your general health.

A lung operation is major surgery and you need to be well enough to cope with it. Before surgery you will have tests to measure how well your lungs are working. A surgeon who is an expert in lung surgery will do your operation.

Non-small cell lung cancer (NSCLC)

Surgery can be used in early stage (stage 1 and stage 2) non-small cell lung cancers and, occasionally, in some stage 3 cancers.

Small cell lung cancer (SCLC)

Doctors rarely advise surgery for small cell lung cancer because it has usually spread outside the lung. It may sometimes be an option if the cancer is very small and your doctor is confident it has not spread. You will need chemotherapy after surgery.

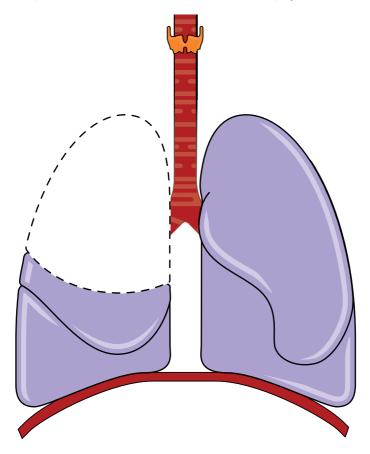
Types of operation

The operation you have depends on the size and position of the cancer. The three main types of operations to remove lung cancer are:

Lobectomy

This is an operation to remove one of the lobes of the lung. About a third to a half of your lung will be removed.

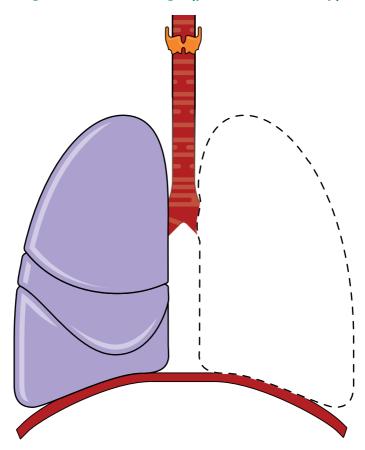
Removing one of the lobes of the lung (lobectomy)



Pneumonectomy

This is an operation to remove one of your lungs. You can still breathe normally with only one lung. If you had breathing difficulties before the operation, you may still be breathless afterwards.

Removing one of the lungs (pneumonectomy)

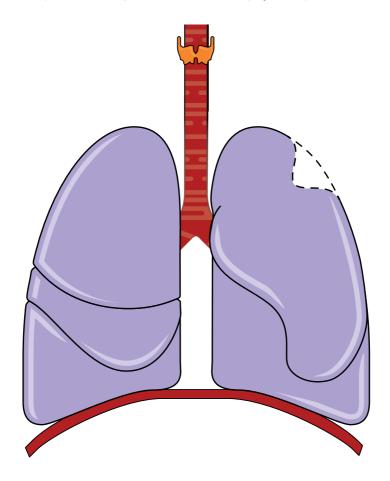


Wedge resection or segmentectomy

These operations remove a very small amount of the lung. You may have this if you have a very early lung cancer. It can also be done if the lung is too damaged to safely have a lobectomy.

A segmentectomy removes a slightly larger part of the lung than a wedge resection.

Removing a small part of the lung (wedge resection)



Open surgery

Surgery for lung cancer usually involves opening the chest between your ribs and sometimes cutting a rib. This is called a thoracotomy. You will have a 10–20cm-long scar around the side of your chest afterwards.

Video-assisted thoracoscopic surgery (VATS)

Sometimes surgeons use a different type of surgery called video-assisted thoracoscopic surgery (VATS). It's a less invasive way of doing lung surgery and is also called keyhole surgery. It's not suitable for everyone and is only carried out by surgeons who have been specially trained to do it.

The surgeon makes several small 2cm cuts in the skin and puts a thoracoscope (see pages 24–25) with a video camera attached into the chest. The camera sends images of inside the chest to a computer screen so the surgeon can see. They pass small instruments through the cuts to remove the cancer.

After VATS there is a much smaller scar than with open surgery and people usually have less pain afterwards and recover faster.

Removing lymph nodes

During an operation to remove the cancer, your surgeon also removes lymph nodes close to the cancer. The lymph nodes will be examined under a microscope to check for cancer cells

If the lymph nodes contain cancer cells, they will have been removed. Knowing if the cancer has spread to the lymph nodes also helps your doctors decide if you need further treatment with chemotherapy or radiotherapy.

If you have questions or would like to know more, talk to your doctor or specialist nurse to make sure you understand what surgery involves.

Before your operation

Before your operation, you may have an appointment at a pre-operative assessment clinic. You will have tests to check how well your lungs are working and tests to check your general health. These may include blood and urine tests, a chest x-ray or a recording of your heart (ECG). Some people have further heart tests or scans, such as a brain scan, to be certain that the cancer has not spread.

You can ask questions and talk over any concerns you have about the operation. If you smoke, you will be advised to give up before your operation. Stopping smoking may help you to recover quicker and spend less time in hospital.

Tell the nurses if you might have problems when you go home. This may be, for example, if you live alone, have several flights of stairs to climb or care for someone else. They can start to arrange help for you when you go home.

You will go into hospital the day of your operation or the day before. The nurses may give you elastic stockings (TED stockings) to wear during and after the operation to help prevent blood clots.

After your operation

You will have regular x-rays after your operation to make sure your lung is working properly.

The nurses and your physiotherapist will encourage you to start moving around as soon as possible. This is important to help with your recovery. They will show you some simple breathing exercises to help prevent chest infections and other possible complications. Even if you have to stay in bed it's important to keep moving your legs regularly. This helps your circulation and prevents blood clots. You'll be given support stockings (TED stockings) to wear. Keep wearing them until the nurses advise that you can stop.

Your wound

If you don't have dissolving stitches, you'll usually have your stitches removed about 7–10 days after your operation.

A wound infection can be a complication of surgery. The nurses and surgeon will check your wound regularly while you are in hospital. Signs of a wound infection include warmth, redness or swelling around the wound, or discharge. You may also feel unwell with a fever. Tell your nurse or doctor if you have any of these symptoms after you go home.

Drips and drains

After your operation you'll be given fluids into a vein in your hand or arm, called a drip or an intravenous infusion. Once you're eating and drinking normally again it's taken out.

You will have a tube into your chest draining fluid and air into a large bottle (called a chest drain). It's usually taken out after a few days.

Pain

After surgery it's normal to have some pain or discomfort but this can usually be controlled. You can have pain relief in different ways:

- into a vein (intravenously)
- into the space around your spinal cord
- as an injection into a muscle
- as tablets.

It's important to have your pain well controlled so that you can breathe properly. This can reduce your risk of developing chest infections. Always let the doctor or nurses know if you are in any pain, so they can treat it as soon as possible.

Pain control through a pump

You may have painkillers given into a vein through a syringe connected to a pump. This can be set to give you a continuous dose of painkiller. You may have a handset you can press to give you more painkillers if you feel sore. The nurses set the pump so you cannot have too much painkiller (an overdose). So it's safe to press it whenever you're uncomfortable.

Pain control in the chest (local anaesthetic)

Some people are given painkillers directly into the area around the lung. You have it through a small tube put into the chest while you are still asleep. The doctor usually removes this after a few days. This is called an epidural or a paravertebral catheter.

You will be given painkiller tablets to take when you go home. You may have mild discomfort or pain in your chest for up to several weeks or months after surgery.

Some people have pain that starts weeks or months after their operation. This can happen if nerve endings that were damaged during surgery start to grow back. Talk to your specialist if this happens so that they can give you the right painkillers to control it.

'Although a big operation, it wasn't as bad as I anticipated because the pain control and after-care were so excellent.'

Ken

Going home

You will usually be ready to go home about 3–7 days after your operation.

Before you go home, you'll be given an appointment for the outpatient clinic to see the surgeon and specialist nurse. At this appointment they will check your wound is healing properly and you are recovering well.

They will also tell you more about the results of your operation, the stage of the cancer and any further treatment you might need. This is a good opportunity to ask any further questions you have.

At home you can gradually build up your strength and fitness with gentle exercise. Check with your doctor or physiotherapist which types of exercise are suitable for you. It can take many weeks, or even months, to recover from a lung operation, although some people recover more quickly than others.

We have more information about recovering after treatment (see pages 84–87).

Driving

Your doctor will tell you when it's safe for you to start driving again after your surgery. It can take about 4–6 weeks for you to be fit enough. At first, you may find that the seatbelt presses on your wound and makes it sore. You can buy padding for seatbelts that may help to reduce this.

Some car insurance policies give specific time limits for not driving after chest surgery – check with your insurance company.

Someone having chemotherapy

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. They work by disrupting the way cancer cells grow and divide, but they also affect normal cells.

The chemotherapy you have depends on the type of lung cancer you have, its stage (see pages 29–31) and how side effects are likely to affect you.

You can have chemotherapy for different reasons, depending on your situation. Your cancer doctor and specialist nurse will explain the aims of your treatment.

Chemoradiation

Chemoradiation means having your course of radiotherapy at the same time as you have your chemotherapy treatment. This is instead of finishing your course of chemotherapy and, after a short break, starting radiotherapy.

Chemoradiation is often used when the cancer is locally advanced (see page 30). Because chemoradiation involves having two treatments at the same time, you have more side effects to cope with. People need to be well enough to cope with these, but there's lots that can be done to manage side effects.

Small cell lung cancer (SCLC)

Chemotherapy is the main treatment for SCLC. Cancers that grow more quickly often respond better to chemotherapy than to other treatments.

It may be given:

- at the same time as radiotherapy (called chemoradiation) to make treatment work better
- after lung surgery (this is rare) to reduce the risk of the cancer coming back
- to control the cancer, help you to live for longer and improve your symptoms.

Non-small cell lung cancer (NSCLC)

Chemotherapy to treat non-small cell lung cancer may be given:

- before surgery or radiotherapy to try to shrink (downstage) the cancer
- after surgery or radiotherapy to reduce the risk of the cancer coming back (called adjuvant chemotherapy)
- at the same time as radiotherapy (called chemoradiation) to make treatment work better
- to control the cancer, help you to live for longer and improve your symptoms.

The drugs used

You usually have a combination of at least two drugs, but you can have treatment with a single drug. With both types of lung cancer you often have either cisplatin or carboplatin with one of these drugs:

- etoposide
- vinorelbine
- gemcitabine
- paclitaxel
- docetaxel
- pemetrexed.

Other chemotherapy drugs may also be used. Your doctor or nurse will give you more information. We have more information about individual chemotherapy drugs and some combined drugs.

If you need more treatment

If the cancer comes back or the chemotherapy didn't work well, you can usually have further chemotherapy with different drugs.

If you have SCLC, your specialist may recommend a combination of the chemotherapy drugs cyclophosphamide, adriamycin or vincristine (CAV for short). Or you may have a drug called topotecan that you can take as a tablet. We have information about CAV and topotecan we can send you.

Docetaxel or pemetrexed may be used to treat NSCLC that comes back. Sometimes, targeted therapy drugs (see pages 67–69) are given with chemotherapy.

How you have chemotherapy

You have the treatment in the chemotherapy day unit and go home after it. Occasionally some people need to stay in hospital for a couple of days.

Most drugs are given into a vein (intravenously), but some are given as tablets.

If you are having chemotherapy into a vein, a nurse will put a small tube (cannula) into a vein in your hand or arm. Or you may have a soft plastic tube called a central line or PICC line put into a vein. We have more information about central lines and PICC lines.

You have chemotherapy into the vein as one or more sessions of treatment. A nurse will give you the chemotherapy drugs through a drip (infusion) or through a syringe.

Each session takes a few hours. After the session, you have a rest period of a few weeks. The chemotherapy session and the rest period is called a cycle of treatment. Most cycles are three weeks. Your doctor or nurse will explain more about this. You usually have between 4–6 cycles.

Side effects

Chemotherapy drugs can cause side effects. Many of these can be controlled with medicines and will usually go away when your treatment finishes. Your doctor or nurse will tell you more about what to expect. Always tell them about your side effects, as there are usually ways they can be controlled.

Risk of infection

Chemotherapy can reduce the number of white cells in your blood. This will make you more likely to get an infection. When they are low, it's called neutropenia.

Contact the hospital straight away on the contact number you've been given if:

- your temperature goes over 37.5°C (99.5F) or over 38°C (100.4F), depending on the advice given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection this can include feeling shaky, a sore throat, a cough, diarrhoea or needing to pass urine a lot.

Your white cells usually increase steadily and return to normal before your next treatment. You will have a blood test before having more chemotherapy. If your blood cells are still low, your doctor may delay your treatment for a short time.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding you can't explain. This includes nosebleeds, bleeding gums, blood spots or rashes on the skin. Some people may need a drip to give them extra platelets.

Anaemia (low red cells)

Chemotherapy can reduce the number of red cells in your blood. These cells carry oxygen around the body. If they are low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red cells (blood transfusion).

Tiredness

Feeling very tired is a common side effect. It's often worse towards the end of treatment and for some weeks after it's finished. Try to pace yourself and get as much rest as you need. It helps to balance this with some gentle exercise, such as short walks. If you feel sleepy, don't drive or operate machinery.

Feeling sick

This may happen in the first few days after chemotherapy. Your doctor will prescribe anti-sickness (anti-emetic) drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist explains to you. It's easier to prevent sickness than to treat it after it has started.

If you still feel sick or are vomiting, contact the hospital as soon as possible. They can give you advice and change the anti-sickness drug to one that works better for you.

'When I came home from my first chemotherapy, I felt quite sick. But once I started getting the right anti-sickness medication, it cleared away.'

Pam

Sore mouth

Your mouth may become sore and you may get ulcers. This can make you more likely to get an infection in your mouth. Gently clean your teeth and/or dentures morning and night and after meals. Use a soft-bristled or children's toothbrush. Your nurse might ask you to rinse your mouth regularly or use mouthwashes. It's important to follow any advice you are given and to drink plenty of fluids.

Tell your nurse or doctor if you have any problems with your mouth. They can prescribe medicines to prevent or treat mouth infections and reduce any soreness.

Constipation

Some drugs may make you constipated and cause tummy pain. Drinking at least two litres of fluids (three and a half pints) every day will help. Try to eat more foods that contain fibre (such as fruit, vegetables and wholemeal bread) and take some regular, gentle exercise. Your doctor can prescribe laxatives to help you.

Hair loss

Your cancer doctor or nurse will tell you if the chemotherapy drugs you are going to have cause hair loss.

If the drugs cause hair loss, you usually lose all the hair on your head. Your eyelashes, eyebrows and other body hair may also thin or fall out. This usually starts after your first or second cycle of chemotherapy. It is almost always temporary and your hair will grow back after chemotherapy ends. It is important to cover your head to protect your scalp when you are out in the sun until your hair grows back. Your nurse can give you advice about coping with hair loss.

Numbness or tingling in hands or feet

These symptoms are caused by the effect of some drugs on nerves. It's called peripheral neuropathy. You may also find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes, but in some people they may never go away. Talk to your doctor if you are worried about this.

Changes in hearing

Cisplatin can affect your hearing. You may have a hearing test before you start treatment. During treatment you may get ringing in your ears (tinnitus) and lose the ability to hear some high-pitched sounds. Tinnitus usually gets better after treatment ends. Some hearing changes can be permanent. Tell your doctor if you notice any changes in your hearing.

Contraception

Your doctor will advise you not to get pregnant or father a child while having chemotherapy. This is because the drugs may harm an unborn baby.

Sex

If you have sex within the first couple of days of having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluid.

Fertility

Chemotherapy may affect your fertility (being able to get pregnant or father a child). If you are worried about this, it's important to talk to your doctor or nurse before treatment starts.

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy for NSCLC

Radiotherapy is a main treatment for non-small cell lung cancer. It may be given:

- to try to cure early cancer if you cannot have an operation (called radical radiotherapy)
- after surgery to reduce the risk of cancer coming back (called adjuvant radiotherapy)
- at the same time as chemotherapy when the cancer is locally advanced (called chemoradiation see page 49)
- to control symptoms when lung cancer has spread to other parts of the body (called palliative radiotherapy).

Our booklet **Understanding radiotherapy** has more information about the treatment and its side effects. Visit be.macmillan.org.uk or call 0808 808 00 00 to order a copy.

Someone having radiotherapy

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Radiotherapy for SCLC

Radiotherapy in people with small cell lung cancer may be given:

- at the same time as chemotherapy (called chemoradiation) when the cancer has not spread to other parts of the body
- after chemotherapy when the cancer has responded well to treatment, even if SCLC is extensive (see page 31)
- to the head to prevent any lung cancer cells that may have spread developing into a secondary cancer in the brain (see page 31)
- to control symptoms when lung cancer has spread to other parts of the body (called palliative radiotherapy).

Having radiotherapy

The treatment is given in the hospital radiotherapy department. The number of treatments you have, and the length of time they take, will depend on the stage of the cancer and the aim of the treatment.

If you are having radical or adjuvant radiotherapy, you usually have a course of radiotherapy for between 4–7 weeks. This will be as a series of short daily sessions. Each treatment takes 10–15 minutes and they are usually given Monday–Friday with a break at the weekend. Sometimes radiotherapy is given three times a day over a shorter number of weeks. This is called CHART radiotherapy (see pages 61–62).

If you are having palliative radiotherapy, you will have a shorter course of treatment, which will usually only lasts up to about two weeks (see page 64). Treatment is given Monday–Friday with a break at the weekend. Radiotherapy can be given in two ways. Usually it is given by high-energy x-rays, which are aimed at the lung from a radiotherapy machine. This is called **external beam radiotherapy**.

Some people may have radiotherapy given from inside the body, called **internal radiotherapy** or **brachytherapy**. The doctor uses a bronchoscope (see page 22) to place a small piece of radioactive material in the lung or airway next to the tumour.

Planning your radiotherapy

Radiotherapy has to be carefully planned to make sure it's as effective as possible. It's planned by a cancer specialist (clinical oncologist) and it may take a few visits.

On your first visit to the radiotherapy department, you'll be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated.

You may need some small marks made on your skin to help the radiographer (who gives you your treatment) position you accurately and to show where the rays will be directed. These marks must stay visible throughout your treatment, and permanent marks (like tiny tattoos) are usually used. These are extremely small, and will only be done with your permission. It may be a little uncomfortable while they are done.

Treatment sessions for external beam radiotherapy

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment you'll be alone in the room, but you can talk to the radiographer who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Other types of external radiotherapy

CHART for non-small cell lung cancer

Chart stands for **c**ontinuous **h**yper-fractionated **a**ccelerated **r**adiotherapy.

Instead of one session of radiotherapy a day for several weeks, with CHART you have three sessions a day, including weekends. But you have it over fewer weeks. Reducing time between treatment sessions means there is less time for fast-growing cancer cells to recover. You usually have to stay in the hospital or somewhere close by during treatment.

The total dose of radiotherapy is the same whether you have standard radiotherapy or CHART.

Studies show CHART may work better than standard radiotherapy for certain people with NSCLC. It may be a possible treatment if you have:

- stage 1 or 2 NSCLC and surgery is not possible.
- stage 3 NSCLC and you aren't well enough to have chemotherapy and radiotherapy together (chemoradiation).

Your doctor can talk to you about whether CHART may be suitable for you. You may have to travel to another hospital to have it.

We can send you more information about CHART.

Stereotactic radiotherapy for NSCLC

Stereotactic ablative radiotherapy (SABR) is a specialised type of radiotherapy. Doctors use scans and specialist machinery to make the radiotherapy beams more precise. This means they can reach small cancers with a high dose of radiotherapy but only give a very low dose to healthy tissue around the tumour. This helps to reduce side effects.

SABR may be used to treat NSCLC that is small when surgery is not possible. It is only suitable for some people and you may need to go to another hospital to have it.

You usually have it over a shorter period of time than standard external radiotherapy – for example, three, five or eight treatments over two weeks.

We can send you more information about stereotactic ablative radiotherapy (SABR).

Preventative radiotherapy to the brain for SCLC

When SCLC has responded well to treatment, doctors sometimes recommend having radiotherapy to the brain. This is called prophylactic cranial radiotherapy (PCR) or prophylactic cranial irradiation (PCI). With SCLC, there is a risk that tiny numbers of cancer cells may have spread to the brain. PCR helps to prevent any cancer cells from developing in the brain.

During treatment you may have a soft clamp fitted to each side of your head to hold it exactly still. This is to make sure that the precise area is treated. Or before treatment starts they may use a see-through perspex device or a plastic mesh to make a mould that fits around your head. This helps you stay in position during treatment.

PCR is usually given daily, Monday–Friday. The number of sessions will depend on your individual situation. Common side effects include feeling very tired and sleepy, and losing the hair on your head, but this is usually temporary.

) We have more information about prophylactic cranial radiotherapy (PCR) that we can send you.

Internal radiotherapy

Internal radiotherapy can be given if the tumour is blocking one of the airways. It helps to open up the airway. The radiotherapy is given directly to the tumour and healthy tissue is only slightly affected. You usually have only one session of treatment. But the treatment can be repeated two or three times, depending on the dose of radiotherapy you need.

The doctor passes a thin tube (catheter) down your nose or throat into the lung using a bronchoscope (see page 22). They place a small piece of solid radioactive material (the source) inside this tube and next to the tumour. The doctor leaves it in place for a few minutes to give you the treatment and then removes it.

Palliative radiotherapy

Sometimes radiotherapy is given to shrink the cancer, reduce symptoms and improve your quality of life. This is usually when the cancer is very advanced in the lung and/or has spread to other parts of the body. This is called palliative radiotherapy.

You can have radiotherapy to the chest to improve breathlessness, chest pain, a cough or coughing up blood. It shrinks the tumours and helps to reduce your symptoms. You may have a short course over a few days or sometimes a higher dose is given over two weeks. Your cancer doctor or nurse will explain more about this.

Doctors may use radiotherapy to treat superior vena cava obstruction. This is when the cancer is pressing on a vein in the chest and blocking the blood flow. There's more information about this on pages 76–77.

Radiotherapy can also be given to relieve pain if the cancer has spread to areas such as the bones. This can usually be given over one or two treatments.

Side effects of radiotherapy to the chest

You may develop side effects over the course of your treatment. These usually disappear gradually over a few weeks or months after treatment finishes. Your doctor, nurse or radiographer will discuss this with you so you know what to expect. Let them know about any side effects you have during or after treatment, as there are often things that can be done to help. It's not unusual to feel worse before you start to feel better. Some people can find this a very difficult time and they may feel low or even depressed for a while. The clinical oncologist can advise you about what to expect.

Problems with swallowing

After 2–3 weeks you may have difficulty swallowing, heartburn or indigestion. This is because radiotherapy can cause inflammation in the gullet (oesophagus).

These side effects can be uncomfortable but your doctor can prescribe medicines to reduce them. If you don't feel like eating, or have problems with swallowing, you can replace meals with nutritious, high-calorie drinks. You can get these from most chemists and some can be prescribed by your GP.



Our booklets **Eating problems and cancer** or **The building-up diet** have some helpful hints.

Tiredness

This is a common side effect and may continue for months after treatment is over. During treatment, you'll need to rest more than usual, especially if you have to travel a long way for treatment each day. But try to balance this with some gentle exercise, such as short walks.



Our booklet **Coping with fatigue** has tips to help you cope with tiredness.

Skin

The skin in the area being treated sometimes gets dry and irritated. Avoid using perfumed soaps or body wash during treatment as they could irritate the skin. You'll be given advice on looking after your skin. Your doctor can prescribe cream to soothe it if it becomes sore.

Hair loss

This only happens in the treatment area. Men may lose hair on their chest. The hair usually grows back, although occasionally hair loss is permanent.

Any side effects should disappear gradually once your treatment is over, but it's important to tell your doctor if they continue.

Late effects

Sometimes radiotherapy for lung cancer may cause long-term side effects. These are side effects that begin during treatment but don't go away, or side effects that develop months or years later.

The lungs may become inflamed or the tissue can become scarred (fibrosis). Let your cancer doctor or specialist nurse know if you have a cough or are short of breath.

Sometimes the gullet can become narrower, causing difficulty in swallowing. In some people, the bones in the chest area may become thinner and this may cause pain in that area.

Most people won't get late effects. But if you notice any symptoms, always tell your cancer doctor or nurse.

Targeted therapies

Targeted therapies work by interfering with the way cancer cells signal or interact with each other, to stop them growing and dividing.

They are usually used to treat advanced non-small cell lung cancer (NSCLC). Clinical trials are still trying to find out if targeted-therapy drugs are helpful in small cell lung cancer. The two types that are used are cancer growth inhibitors and monoclonal antibodies. These drugs are not all widely available in the UK. Your doctor will tell you if they are suitable for you.

Some people are given targeted therapy drugs in a clinical trial.

We can send you more information about targeted therapies. You can also speak to our cancer support specialists on 0808 808 00 00. We also have information on what you can do if a treatment isn't widely available.

Cancer growth inhibitors

Many types of cancer cells have chemicals on their surface called growth factors. These send chemical signals to cells that control how the cancer cells grow and divide. Cancer growth inhibitor drugs used in lung cancer block these signals and prevent the cells from growing.

But they only work for NSCLCs that have an abnormal form of a protein called epidermal growth factor receptor (EGFR). You have tests for EGFR on the cancer cells (from your lung biopsy or previous surgery) to find out whether these drugs are likely to be helpful.

Erlotinib (Tarceva[®]), gefitinib (Iressa[®]) and afatanib (Giotrif[®]) are all cancer growth inhibitors. They may be used to treat NSCLC that has spread to the area surrounding the lung (locally advanced) or to other parts of the body.

These drugs are given as tablets. The side effects can include a rash, diarrhoea, feeling sick and tiredness.

Erlotinib can be given as a first treatment for lung cancer. It can also be given if the cancer comes back after chemotherapy, or if chemotherapy isn't working well. We have more information about erlotinib that we can send you.



Gefitinib can also be used as a first treatment for lung cancer. We have more information about gefitinib that we can send you.

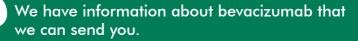
Afatanib can be used as a first drug treatment if you have not had another EGFR drug before.

Another cancer growth inhibitor drug called crizotinib (Xalkori[®]) is sometimes used. For this drug, doctors test the cancer cells for a protein called anaplastic lymphoma kinase (ALK). Nintedanib is another targeted therapy drug that may be given along with the chemotherapy drug docetaxel to people who have already had treatment.

Monoclonal antibodies

Monoclonal antibodies recognise certain proteins (called receptors) found on some types of cancer cells. Bevacizumab (Avastin[®]) is a monoclonal antibody that attaches to receptors on some lung cancer cells. It stops them connecting with a different protein that helps the cell to grow.

Bevacizumab is not widely available on the NHS. Some people may be given it in a clinical trial.



Tumour ablation

Tumour ablation are treatments that may use heat (radiofrequency ablation) or laser light (photodynamic therapy) to destroy cancer cells. Doctors sometimes use these treatments for small, very early stage lung cancers.

Other tumour ablation treatments use cold (cryotherapy), an electrical current (diathermy) or a laser to help shrink the cancer. These can be given to relieve breathlessness when the tumour is growing into the windpipe or main airways into the lungs (bronchi – see page 8).

Radiofrequency ablation

This treatment uses heat to destroy cancer cells. It's usually only used when a person has a very early stage cancer and other treatments are not suitable.

You may be given a local anaesthetic and sedative to make you sleepy before this treatment or you may have a general anaesthetic. You usually need to stay in hospital overnight to have the treatment.

Your doctor will place a needle into the tumour, using a CT scan (see page 21) to make sure it is in the exact place. Radio waves are passed through the needle into the tumour to heat and destroy the cancer cells. There are few side effects with this treatment. It's common to have some pain or discomfort but you will be given painkillers to control this. You may also feel tired afterwards.

We can send you more information about radiofrequency ablation.

Photodynamic therapy (PDT)

This treatment uses lasers or other light sources, combined with a light-sensitive drug, to destroy cancer cells. PDT can sometimes be used to treat some small, early lung cancers in people who can't have surgery.

You have a light-sensitive drug that makes the cancer cells more sensitive to the laser. You are given this as a liquid into a vein.

When the drug is taken up by the cancer cells, the doctor directs the laser light at the tumour with a bronchoscope (see page 22). The laser makes the light-sensitive drug destroy cancer cells.

PDT makes you temporarily sensitive to light. You may need to avoid bright light for up to six weeks by covering your skin and wearing sunglasses in daylight.

Other side effects of PDT include breathlessness and a cough. You may also have some mild pain or discomfort in your chest. Your doctor can give you more information. PDT is only available at some hospitals.

We can send you more information about photodynamic therapy (PDT).



Treating blocked or narrowed airways

Doctors usually use the following treatments to relieve symptoms when the cancer is causing a blockage or narrowing the airways. PDT (see previous page) is occasionally used to treat an advanced cancer.

Cryosurgery

Cryosurgery (or cryotherapy) uses extreme cold to freeze and destroy cancer cells. It is mainly used if the tumour grows into the main lung airway (trachea) and causes it to narrow. This isn't common but if it happens you can become very breathless.

You have a general anaesthetic for this treatment. While you're asleep, the doctor will use a bronchoscope (see page 22) to guide a thin, flexible tube with a rounded end (probe) close to the tumour. Liquid nitrogen, which freezes and destroys the cancer cells, is passed through the probe into the tumour.

You can have this treatment again if the tumour grows back.

Diathermy (or electrocautery)

This treatment uses an electrical current to destroy cancer cells. If your airway is blocked, diathermy can make it easier for your doctor to give you internal radiotherapy (see page 63). Sometimes, the two treatments can be given together. You usually have diathermy under a general anaesthetic.

Your doctor will use a bronchoscope (see page 22) to guide a probe into your windpipe. They pass an electrical current through the probe into the tumour to destroy cancer cells.

Laser therapy

Doctors can use laser therapy to shrink the cancer to prevent it from blocking the airways.

Laser therapy doesn't destroy the tumour completely, but it can help to reduce or get rid of breathlessness.

You usually have laser therapy under a general anaesthetic. The surgeon passes a flexible tube through a bronchoscope (see page 22) to aim the laser beam at the tumour. The laser beam shrinks as much of the tumour as possible.

There aren't usually any side effects from laser therapy. You can go home the same evening or the next day. If you've had an infection in your lung, you may need to stay in hospital for a few days for antibiotic treatment and physiotherapy. Laser treatment can be used again. It is sometimes given together with radiotherapy, which can make the effects last longer.

Controlling symptoms

Some people may have ongoing symptoms, such as breathlessness or a cough, or may develop new symptoms during their illness. Treatment with chemotherapy and radiotherapy can help to relieve symptoms but there are also other ways to manage and control symptoms.

You may be referred to a doctor or nurse who is an expert in symptom control. They're sometimes called palliative care experts.

If you have any new symptoms, always tell your doctor or cancer nurse straight away. Some lung cancers produce hormones or antibodies that upset the body's chemical balance. These may cause symptoms such as feeling sick, being sick or feeling very drowsy.

We have a booklet **Controlling the symptoms of cancer**, which you may find helpful.

Breathlessness

Breathlessness is a common symptom in people with lung cancer. It can be distressing to deal with, but there are treatments (see pages 73–74) and drugs that can help to relieve or manage it. Breathing and relaxation exercises can also help make living with breathlessness easier. Some people find complementary therapies helpful.

We have more information on cancer and complementary therapies. We can also send you information about managing breathlessness, including a CD called **Relax and breathe**. 'My breathing gradually improved after I came out of hospital, but I still found that sudden activity could leave me gasping. So I started doing breathing and relaxation exercises and going for short walks, which helped build up my lung capacity.'

Frances

Stents for breathlessness

If the cancer presses on the airway, it can become narrow. A small tube called a stent can be used to open up the airway to help you breathe more easily. You usually have a stent put in under a general anaesthetic.

The doctor places the stent inside the airway using a bronchoscope (see page 22). The stent is folded flat when it's first inserted, and as it comes out of the bronchoscope, it opens up like an umbrella. This pushes the walls of the narrowed airway open. It can stay in your lung permanently.

Superior vena cava obstruction (SVCO)

If the cancer presses on a vein in the chest (the vena cava) that carries blood to the heart, it may block the blood flow. This is called superior vena cava obstruction (SVCO).

SVCO can cause breathlessness, a feeling of fullness in the face and swelling in the face, neck and chest. It needs to be treated quickly. You'll be given oxygen and drugs to relieve the symptoms. The treatment you have will depend on your situation. Doctors may use radiotherapy to shrink the tumour and relieve the symptoms. Some people have chemotherapy, or they have a stent inserted into the vein to help the blood flow through it.

We can send you more information about superior vena cava obstruction (SVCO).

Cough

There are different treatments that can help a cough. Some types of painkiller tablets can help. Other drugs can be given as a vapour that you inhale. A short course of radiotherapy can also help to improve a cough.

Pleural effusion

Cancer in the lung can cause fluid to build up between the layers that cover the lung (pleura – see page 8). This is called pleural effusion. Your doctor may insert a needle (cannula) into the area attached to a tube that drains the fluid into a drainage bag or bottle.

Sometimes, it's possible to try to seal the two layers of the pleura together. Doctors use talc mixed with saline (sterile salt water) and infuse it through a small tube into the space between the two layers, which helps them stick together. This is called pleurodesis.



We have more information about pleural effusion.

Pain

If you have pain, it's important to tell your doctors and nurses so they can treat it. There are many different ways to control pain. Your doctor or specialist nurse can explain the best way to manage the pain in your situation.

Painkiller drugs can be taken by mouth, as an injection or sometimes as a continuous infusion through a small electrical pump.

If you have cancer that has spread to your bones and it causes you pain, you may be given bone-strengthening drugs called bisphosphonates. We have information about different bisphosphonate drugs.

Radiotherapy may sometimes be given in a short course for a few days to help bone pain.

Our booklet **Controlling cancer pain** gives more information about how to manage pain. You can visit be.macmillan.org.uk or call 0808 808 00 00 to order a copy.

Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits. If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.



We can send you a free copy of our booklet Understanding cancer research trials (clinical trials).



Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

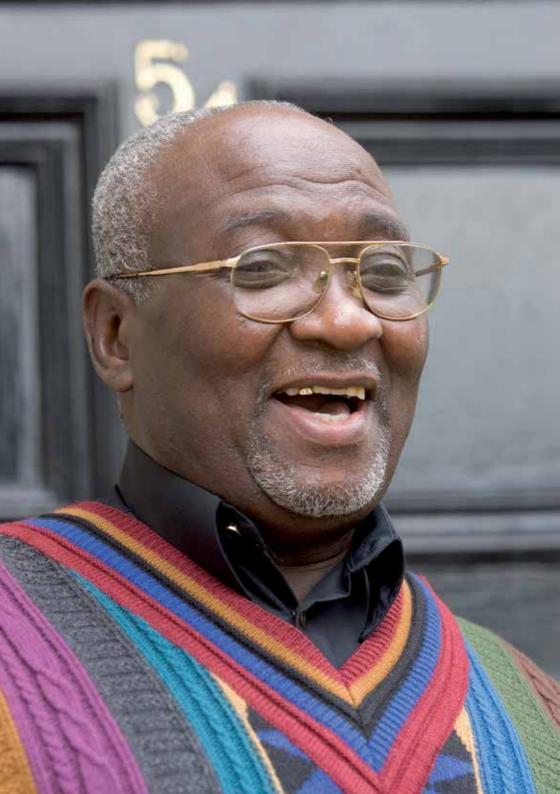
The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

Current research

There are currently many trials for people with lung cancer. Some are looking at how to diagnose lung cancer earlier. Others are looking at giving combinations of chemotherapy drugs in combination with radiotherapy or targeted therapies.

There are also trials looking at new ways of improving symptoms, such as breathlessness or coughing.

Our website **macmillan.org.uk** has information about current clinical trial databases.



AFTER YOUR TREATMENT

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Follow-up

After treatment, you will have regular check-ups and chest x-rays. Your appointments will be every few months at first but eventually they may be once a year. Appointments are a good opportunity for you to talk to your doctor or nurse about any concerns you have. But if you notice any new symptoms between appointments, you can contact your doctor or nurse for advice.

Many people find they get anxious before the appointments. This is natural. It can help to get support from family, friends or one of the organisations listed on pages 116–117. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Driving after lung cancer

Lung cancer may affect your ability to drive safely. If you hold a large goods vehicle (LGV) or a passenger carrying vehicle (PCV) driving licence, you'll need to notify the DVLA (England, Scotland and Wales) or the DVA (Northern Ireland) if you have been treated for lung cancer in the last five years.

There is more information about driving and medical conditions in England, Scotland and Wales on the website at **direct.gov.uk/en/motoring** or you can call **0300 790 6801**.

In Northern Ireland, you can get more information about licensing after cancer from the DVA licensing website at **dvlni.gov.uk/dvlni.aspx** or by calling **0845 402 4000**.

Taking care of yourself

During and after treatment you are likely to feel very tired and you may be coping with some side effects. It's important to take care of yourself to allow your body time to recover. Try to pace yourself and get as much rest as you need. Ask family and friends to help out so you save energy for the things you want to do.

Our booklet **Coping with fatigue** has helpful tips on how to reduce tiredness. Our booklet **Life after cancer treatment** has useful information about keeping healthy and adjusting to life after treatment.

Smoking

If you smoke, it's very important to follow your doctor's advice on smoking. We have more information on stopping smoking we can send you.

Try to eat well

Eating healthily will improve your general health and you'll also feel better and have more energy. Try to eat plenty of fruit and vegetables, more chicken and fish and less red or processed meats.

Even if you don't have much of an appetite, make sure you have regular snacks. There are also supplement drinks (some are available on prescription) you can take to make sure you're getting enough energy and nutrients. Ask your doctor or nurse to refer you to a dietitian if you need more advice. Our booklet **Eating well after cancer treatment** has more information. Our booklet **Diet and cancer** has helpful tips on coping with eating difficulties.

Being active

Taking regular short walks can help to build up your energy levels after treatment and reduce stress. You can gradually build this up to help to improve your lung and heart health.

You can read more about exercise and its benefits in our booklet **Physical activity and cancer treatment**.

Stick to sensible drinking

It's a good idea to stick to sensible drinking guidelines. These recommend men should drink no more than three units of alcohol a day (or 21 a week) and women no more than two units a day (or 14 a week). It's also a good idea to have a couple of alcohol-free days each week.

Emotional help

If you think you may be depressed, or feel helpless or anxious a lot of the time, talk to your cancer specialist or nurse. They can refer you to a psychologist or counsellor who specialises in the emotional problems of people with cancer. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and let you know about services in your area.

Complementary therapies

Some people find that using some complementary therapies help them to relax or cope with treatment side effects. Some hospitals or support groups may offer therapies such as relaxation or aromatherapy. Our booklet **Cancer and complementary therapies** has more information.

Support groups

Self-help or support groups offer a chance to talk to other people who understand what you're going through. You can call us or visit our website for information about support groups in the UK.

> 'I felt very alone after my diagnosis. But this is why the lung cancer support group I'm a part of has been so good. Before I joined, I'd never met anyone else with lung cancer.'

Edward

Online support

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experience, to ask questions, and to get and give advice based on your experience. Our online community at **macmillan.org.uk/community** is a social networking site where you can talk to people in our chat rooms, write blogs, make friends and join support groups.



YOUR FEELINGS AND RELATIONSHIPS

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Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our online community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

> 'Before my treatment, I couldn't stand people talking to me about the cancer. But when I went into hospital, there was a Macmillan nurse who talked to me and explained things to me, and it helped me greatly.'

Arthur

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.



What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

Relationships

The experience of cancer may have improved your relationships with people close to you. The support of family and friends may have helped you cope. But cancer is stressful, and this can have a negative effect on relationships. Any problems usually improve over time, especially if you can talk openly about them.

Your partner

Some couples become closer through a cancer experience. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between couples who've been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse. Even couples that are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help you understand each other.

Our booklets **Cancer, you and your partner** and **Sexuality and cancer** have more information that may help.

Family and friends

Your family and friends may not always understand if you aren't feeling positive about getting on with things, and may not know how big an effect treatment is having on your life. Talking about how you feel will help them give you the support you need.



Our booklet Talking about your cancer has useful tips.

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

Our booklet **Talking to children when an adult** has cancer includes discussion about sensitive topics. There's also a video on our website that may help, at macmillan.org.uk/talkingtochildren

If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit **macmillan.org.uk/learnzone** to find out more.

Our booklet Lost for words – how to talk to someone with cancer has more suggestions if you have a friend or relative with cancer. If you're looking after a family member or friend with cancer, you may find our booklet Looking after someone with cancer helpful. It's based on carers' experiences and has lots of practical tips and information.

We also have more information about supporting someone with cancer at **macmillan.org.uk/carers**



WORK AND FINANCIAL SUPPORT

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Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. There's also lots more information at macmillan.org.uk/work

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- contributory you can get this if you have made enough national insurance contributions
- income-related you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance (DLA) in England, Scotland and Wales. Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 118) or Citizens Advice (see page 117). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**. Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at macmillan.org.uk/gettingfinancialhelp useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 117–119.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful.





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About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All of our information is also available online at **macmillan**. **org.uk/cancerinformation** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- large print
- translations.

Find out more at **macmillan.** org.uk/otherformats If you'd like us to produce information in a different format for you, email us at cancerinformationteam@ macmillan.org.uk or call us on 0808 808 00 00.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets. If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan. org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at macmillan.org.uk/ informationcentres or call us on 0808 808 00 00.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/** selfhelpandsupport

Online community

Thousands of people use our online community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/ community

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial advice

Our financial guidance team can give you advice on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/ financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

> Macmillan's My Organiser app This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

British Lung Foundation

73–75 Goswell Road, London EC1V 7ER **Tel** 03000 030 555 (Mon–Fri, 9am–5pm) **Email** helpline@blf.org.uk **www.lunguk.org** Supports people affected by any type of lung disease.

NHS Smokefree Helpline

Tel 0300 123 1044 (Daily, 7am–11pm) **www.nhs.uk/smokefree** Offers information, advice and support to people who what to give up smoking, and those who have given up and don't want to start again.

NHS Direct – Stop Smoking Wales Tel 0800 0852219 Email

stop.smoking@wales.nhs.uk www.stopsmokingwales.com

Offers information, advice and support in English and Welsh.

NHS Northern Ireland www.nidirect.gov.uk/ smoking

Website contains information, advice and links to support organisations for people in Northern Ireland who want to give up smoking.

Quit

4 Sovereign Close, Wapping, London E1W 3HW **Quitline** 0800 00 22 00 (Daily, 9am–9pm) **www.quit.org.uk** Offers practical help and advice to people who want to stop smoking.

Roy Castle Lung Cancer Foundation

98 Holm Street, Glasgow G2 6SY **Tel** 0333 323 7200 **Email** info@roycastle.org Provides practical and emotional support for those affected by lung cancer.

Smokeline Scotland Helpline Tel 0800 84 84 84

(Mon–Sun, 8am–10pm) **Email** smokeline@ nhs24.scot.nhs.uk **www.canstopsmoking.com** Offers advice and information about how to stop smoking.

General cancer support organisations

Cancer Black Care

79 Acton Lane, London NW10 8UT **Tel** 020 8961 4151

Email

info@cancerblackcare.org.uk www.cancerblackcare.org.uk

Offers information and support for people from ethnic communities.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue, Belfast BT9 6DX **Tel** 0800 783 3339 (Mon–Fri, 9am–1pm) **Email** hello@cancerfocusni.org www.cancerfocusni.org

Offers services to people affected by cancer, including a helpline, counselling and links to local support groups. Cancer Research UK Angel Building, 407 St John Street, London EC1V 4AD Tel 0300 123 1022 www.cancerhelp.org.uk Has patient information on all types of cancer and has a clinical trials database.

Cancer Support Scotland

The Calman Centre, 75 Shelley Road, Glasgow G12 0ZE **Tel** 0800 652 4531 **Email** info@ cancersupportscotland.org **www.cancersupport scotland.org** Runs cancer support groups throughout Scotland. Also offers free complementary

therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices www.macmillan.org.uk/ cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's Centres

2nd Floor Palace Wharf, Rainville Road, London W6 9HN **Tel** 0300 123 1801 **Email** enquiries@ maggiescentres.org **www.maggiescentres.org** Provides information about cancer, benefits advice, and emotional or psychological support.

Penny Brohn Cancer Care

Chapel Pill Lane, Pill, Bristol BS20 OHH **Tel** 01275 371 100 (Mon–Fri, 9.30am–5pm) **Email** helpline@pennybrohn.org **www.pennybrohn cancercare.org** Offers a combination of physical, emotional and

physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Riprap

Att Pauline Hutchinson, University of Sheffield, Sykes House office, St Luke's Hospice, Little Common Lane, Sheffield S11 9NE **www.riprap.org.uk** Developed especially for teenagers who have a parent with cancer.

Tenovus

Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD **Tel** 0808 808 1010 (Mon–Sun, 8am–8pm) **www.tenovus.org.uk** Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

General health information

Health and Social Care in Northern Ireland www.hscni.net

Provides information about health and social care services in Northern Ireland.

Healthtalk Email

info@healthtalkonline.org www.healthtalk.org www.youthhealthtalk.org (site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

National Cancer Institute –National Institute of Health – USA www.cancer.gov

Gives information on cancer and treatments.

NHS Choices

The UK's biggest health information website. Has service information for England. NHS Direct Wales www.nhsdirect.wales.nhs.uk NHS health information site for Wales.

NHS Inform www.nhsinform.co.uk NHS health information site for Scotland.

Patient UK www.patient.co.uk

Provides people in the UK with information about health and disease. Includes evidencebased information leaflets on a wide variety of medical and health topics. Also reviews and links to many healthand illness-related websites.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

BACP House, 15 St John's Business Park, Lutterworth, Leicestershire LE17 4HB Tel 01455 883 300 Email bacp@bacp.co.uk www.bacp.co.uk Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Samaritans

Freepost RSRB-KKBY-CYJK, Chris, PO Box 9090, Stirling FK8 2SA **Tel** 08457 90 90 90 **Email** jo@samaritans.org **www.samaritans.org** Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

UK Council for Psychotherapy (UKCP)

2nd Floor, Edward House, 2 Wakley Street, London EC1V 7LT **Tel** 020 7014 9955 **Email** info@ukcp.org.uk **www.psychotherapy.org.uk** Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Tel 0800 220 674 (Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm) Textphone 0800 243 787 www.nidirect.gov.uk/ money-tax-and-bfits

Provides information and advice about disability benefits and carers' benefits.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

England and Wales www.citizensadvice.org.uk

Scotland www.cas.org.uk

Northern Ireland www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk**

Civil Legal Advice

Tel 0845 345 43 45 (Mon–Fri, 9am–8pm, Sat, 9am–12.30pm) Minicom 0345 609 6677 www.gov.uk/ civil-legal-advice

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

Department for Work and Pensions (DWP) Disability Living Allowance Helpline 0345 712 3456 Textphone 0345 722 4433 Personal Independence Payment Helpline 0345 850 3322 Textphone 0345 601 6677 Carer's Allowance Unit 0345 608 4321 Textphone 0345 604 5312 www.gov.uk/browse/ benefits Manages state benefits in

Manages state benetits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

www.gov.uk

Has comprehensive information about social security benefits and public services.

The Money Advice Service

Tel 0300 500 5000 (Mon–Fri, 8am–8pm, Sat, 9am–1pm) Typetalk 18001 0300 500 5000 www.moneyadvice service.org.uk Runs a free financial health check service and gives advice about all types of financial matters. Has an online chat service for instant money advice.

Money Advice Scotland Tel 0141 572 0237 www.moneyadvice scotland.org.uk

National Debtline (England, Wales and Scotland)

Tricorn House, 51–53 Hagley Road, Edgbaston, Birmingham B16 8TP **Tel** 0808 808 4000 (Mon–Fri, 9am–9pm, Sat, 9.30am–1pm) **www.nationaldebtline.co.uk** A confidential helpline for people with debt problems.

Personal Finance Society – 'Find an Adviser' service www.findanadviser.org

Use the website to find qualified financial advisers in your area.

Unbiased.co.uk

Email contact@unbiased.co.uk www.unbiased.co.uk On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.

Equipment and advice on living with a disability

British Red Cross

UK Office, 44 Moorfields, London EC2Y 9AL **Tel** 0844 871 11 11 **Email** information@redcross.org.uk **www.redcross.org.uk** Offers a range of health and

social care services such as care in the home, a medical equipment loan service and a transport service. **Disability Rights UK** Ground Floor, CAN Mezzanine, 49–51 East Road, London N1 6AH Tel 0300 555 1525 Email enquiries@ disabilityrightsuk.org www.disabilityrightsuk.org.uk Provides information on social security benefits and disability rights. Has a number of helplines for specific support, including information on returning to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)

Ground Floor, Landmark House, Hammersmith Bridge Road, London W6 9EJ **Tel** 0300 999 0004 (Mon–Fri, 10am–4pm) **Email** helpline@dlf.org.uk **www.dlf.org.uk** Provides free, impartial advice about all types of disability equipment and mobility products.

Support for older people

Age UK

Tavis House, 1–6 Tavistock Square, London WC1H 9NA **Tel (England and Wales)** 0800 169 6565 **Tel (Scotland)** 0845 125 9732

Tel (Northern Ireland) 0808 808 7575 (Daily, 8am–7pm)

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line.

Support for carers

Carers UK Tel (England, Scotland, Wales) 0808 808 7777 Tel (Northern Ireland) 028 9043 9843 (Wed–Thu, 10am–12pm and 2–4pm) Email advice@carersuk.org www.carersuk.org Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Advanced cancer and end-of-life care

Help the Hospices

Hospice House, 34–44 Britannia Street, London WC1X 9JG Tel 020 7520 8200 Email

info@helpthehospices.org.uk www.helpthehospices.org.uk Provides information about living with advanced illness. Has a directory of hospice services and practical booklets available free from the website.

Marie Curie Cancer Care

89 Albert Embankment, London SE1 7TP **Tel** 0800 716 146 (Mon–Fri, 9am–5.00pm) **Email** supporter.relation@ mariecurie.org.uk **www.mariecurie.org.uk** Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

YOUR NOTES AND QUESTIONS

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photographs are of models.

Thanks

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With thanks to: Amy Gunnett, Lung Cancer Nurse Specialist; Dr Sam Janes, Consultant Respiratory Physician; Mr Alan Kirk, Consultant Thoracic Surgeon; Dr Rhona McMenemin, Consultant Clinical Oncologist; Dr Noelle O'Rourke, Consultant Clinical Oncologist; and Mr Tom Routledge, Consultant Thoracic Surgeon and Honorary Lecturer. Thanks also to the people affected by cancer who reviewed this booklet, and those who shared their stories.

Sources

We've listed a sample of the sources used in this publication below. If you'd like further information about the sources we use, please contact us at **bookletfeedback@macmillan.org.uk**

European Society for Medical Oncology (ESMO). Early stage non-small cell lung cancer consensus on diagnosis, treatment and follow-up. ESMO Consensus Guidelines. 2014. European Society for Medical Oncology (ESMO). Small-cell lung cancer (SCLC): ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. 2013. National Institute for Health and Care Excellence (NICE). Lung cancer – the diagnosis and treatment of lung cancer. NICE Clinical Guideline. April 2011. Scottish Intercollegiate Guidelines Network (SIGN). Management of lung cancer. 2014.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money

Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

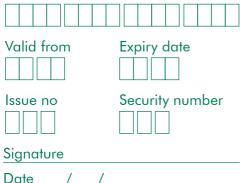
Email

Please accept my gift of £

(Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number



Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay. Non-English speaker? Interpreters available. Braille and large print versions on request.

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