A practical guide to understanding cancer

UNDERSTANDING MESOTHELIOMA

About this booklet

This booklet is about a type of cancer called mesothelioma. It is for anyone who is having tests for mesothelioma or has been diagnosed with it. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of pleural and peritoneal mesothelioma. It explains how they are diagnosed and how they may be treated. It also has information about the feelings you might experience, and how your relationships, work and finances might be affected.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

As this booklet includes information on pleural and peritoneal mesothelioma, not every section will apply to you. For example, the sections on tests and treatments are split depending on which type you have.

You don’t have to read it from start to finish. You can use the contents list on page 3 to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

At the end of this booklet, there are details of other organisations that can help (see pages 129 to 133).

Quotes

Throughout this booklet we have included quotes from people affected by cancer. Some are from the website **healthtalk.org** Others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use. If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Mesothelioma UK provides specialist information and support to people with mesothelioma. You can contact them for free on **0800 169 2409** (Monday to Friday, 8.30am to 4.30pm), or visit **mesothelioma.uk.com**

Contents

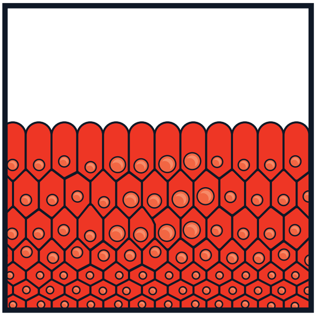
MESOTHELIOMA

What is cancer?

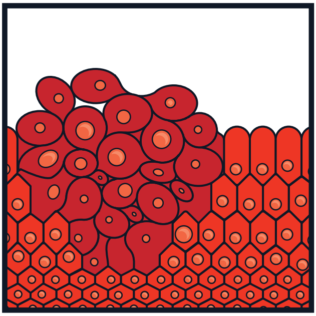
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop 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 pages 8 to 9). 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**.

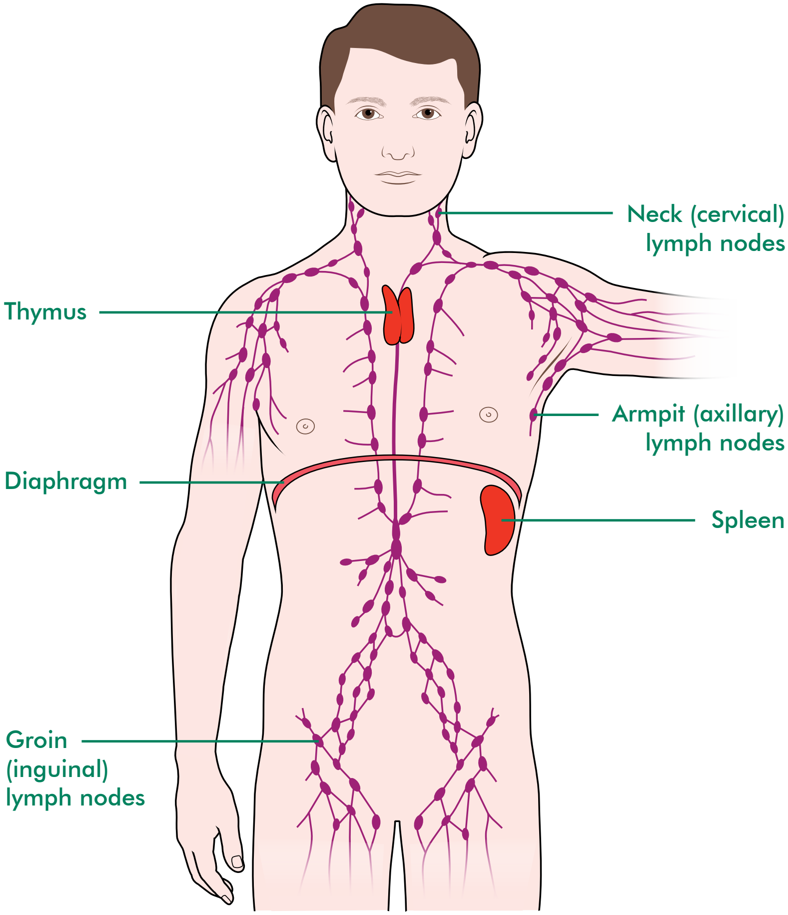
The lymphatic system

The lymphatic system is part of the immune system. It 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. It is made up of organs such as the bone marrow, thymus, spleen and lymph nodes.

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.

Mesothelioma can spread to the lymph nodes in the chest.

The lymphatic system



What is mesothelioma?

In the UK, more than 2,700 people are diagnosed with mesothelioma each year.

Mesothelioma is a cancer of the mesothelium. This is a thin lining (membrane) that covers the outer surface of many of our organs. The mesothelium has different names depending on where it is in the body. For example:

- the mesothelium in the chest is called the pleura
- the mesothelium the abdomen is called the peritoneum.

Cancer of the mesothelium is called malignant mesothelioma. But it is usually known as mesothelioma. Mesothelioma in the chest is called pleural mesothelioma. Mesothelioma in the abdomen is called peritoneal mesothelioma. Pleural mesothelioma is much more common than peritoneal mesothelioma.

Pleural mesothelioma

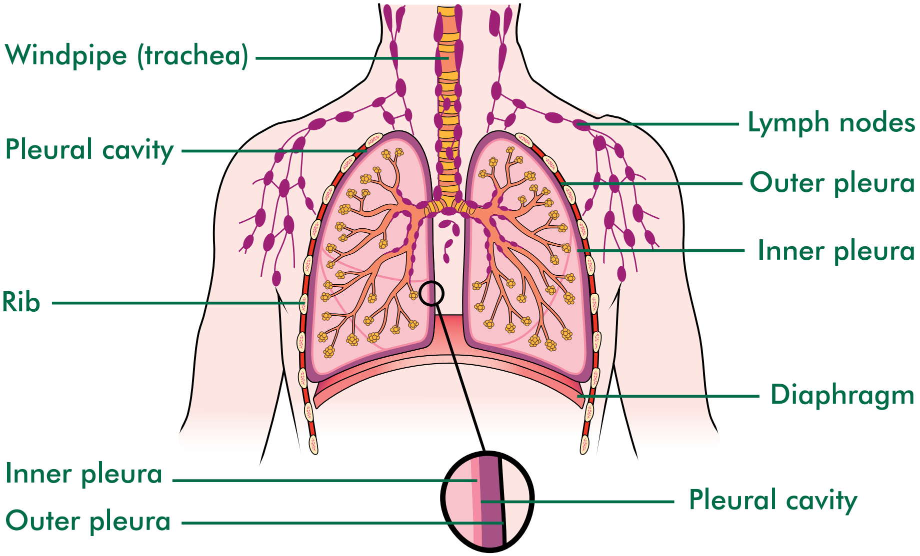
The lungs sit within the chest, on either side of the heart. They supply oxygen to the organs and tissues of the body.

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

The pleura produces a small amount of fluid. This fluid acts as a lubricant, which allows the lungs to move in and out smoothly and helps you to breathe easily.

Mesothelioma in the pleura starts as tiny lumps (nodules) that are usually spread throughout the pleura. These eventually grow together, causing the layers of the pleura to become thicker. This means the lungs and chest cannot move as freely, causing you to feel breathless. Fluid may also collect between the two layers of the pleura. This is called a pleural effusion (see pages 72 to 73).

Structure of the lungs and pleura

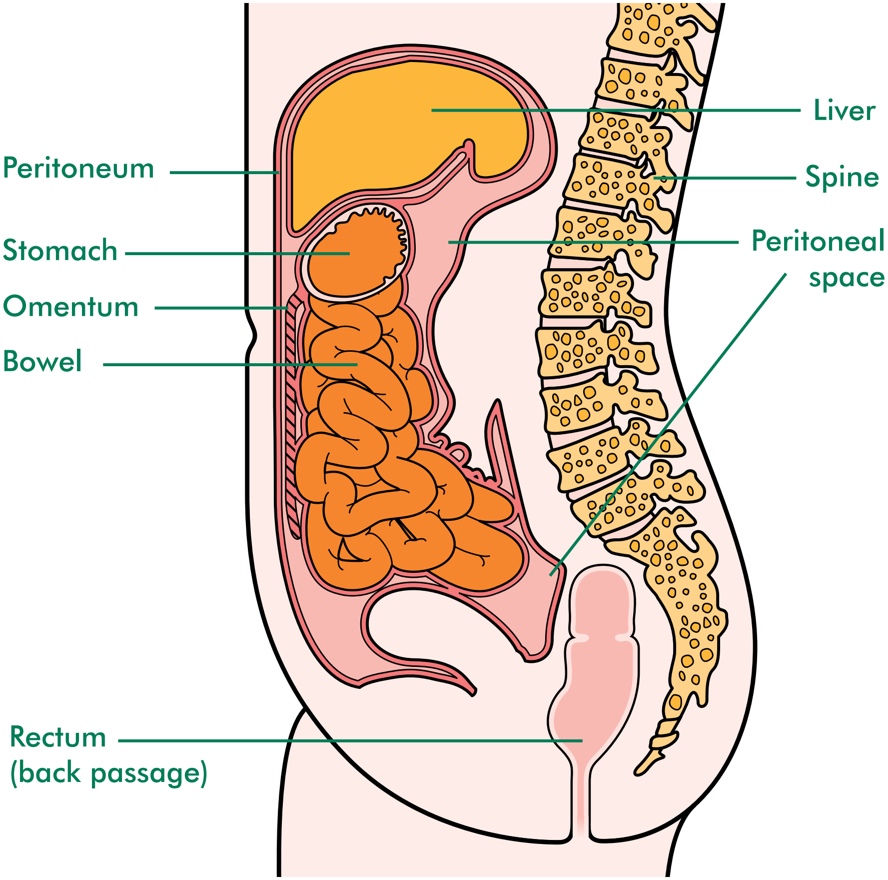


Peritoneal mesothelioma

The organs in the tummy (abdomen) are covered by a lining (membrane) called the peritoneum. It has an inner and outer layer. The inner layer covers the organs in the abdomen. The outer layer lines the abdominal wall.

The peritoneum helps protect the organs in the abdomen and keeps them in place. This is shown as the thick line surrounding the abdominal organs in the illustration opposite. When mesothelioma develops in the peritoneum, it causes the layers of the peritoneum to thicken. Fluid may also collect between the two layers. This is known as ascites (see pages 76 to 77).

Side view of the tummy (abdomen) showing the peritoneum



Cell types of mesothelioma

Pleural and peritoneal mesothelioma can be grouped according to how the cells look under a microscope. There are three main types:

- epithelioid – this is the most common
- sarcomatoid (fibrous)
- mixed (biphasic) – this has both epithelioid and sarcomatoid cells.

Knowing the type of cell involved may give your doctors an idea of how well the mesothelioma will respond to treatment.

Rare types of mesothelioma

Very rarely, mesothelioma may develop in the outer lining of other organs. This includes the heart (pericardial mesothelioma) or the testes (testicular mesothelioma).

Risk factors and causes

Asbestos

Asbestos is the most common cause of mesothelioma. Over 9 out of 10 cases of mesothelioma (90%) are caused by exposure to asbestos fibres. Asbestos is a natural mineral found in many countries.

There are three main types of asbestos:

- blue (crocidolite)
- brown (amosite)
- white (chrysotile).

They were used in UK industries until the ban on imports of blue and brown asbestos in the 1980s, and on all types in 1999. Exposure to blue and brown asbestos is commonly linked with mesothelioma. However, exposure to all types of asbestos is harmful.

Mesothelioma does not usually develop until many years after exposure to asbestos. It can take from 15 to 60 years. But the average is about 30 to 50 years after exposure for pleural mesothelioma. It may be less time for peritoneal.

Pleural mesothelioma

When asbestos is damaged or disturbed (often by hitting, rubbing or handling), it releases tiny fibres. These fibres can be breathed into the lungs. Asbestos fibres are very fine and can get into the smallest airways of the lungs. Once the fibres are in the lungs, the body's defence mechanisms try to break them down and remove them. This leads to inflammation in the lung tissue.

The asbestos fibres can also travel through the lung tissue and settle in the outer lining of the lung (the pleura). Over many years, these fibres can cause pleural mesothelioma or other lung conditions to develop.

Peritoneal mesothelioma

Asbestos fibres can also be swallowed, and some of the fibres can get stuck in the digestive system. They can then move into the outer lining of the abdomen (the peritoneum). Here, they cause swelling and thickening of the lining. This can lead to peritoneal mesothelioma.

Exposure to asbestos

People most likely to have been exposed to asbestos at work include:

- joiners and construction workers
- plumbers
- electricians
- boilermakers
- shipbuilders.

Mesothelioma is five times more common in men than in women. This is because when asbestos was used in these industries, it was mostly men who did these types of jobs.

People who have not worked directly with asbestos can also sometimes develop mesothelioma. For example:

- family members of people who have worked with asbestos and unknowingly brought the dust home on their clothes
- people who lived near asbestos factories
- people who worked in buildings containing asbestos materials that were damaged or disturbed.

If you develop an asbestos-related illness, you may be entitled to certain benefits and compensation (see pages 100 to 113).

Occasionally, mesothelioma develops in people who did not know that they have been exposed to asbestos.

Other causes

The other causes of mesothelioma are not fully understood. In rare cases, mesothelioma has been linked to:

- exposure to radiotherapy
- a mineral called erionite, which has been found in Turkey and North America.

Mesothelioma is not infectious and cannot be passed on to other people.

Doctors don’t know why some people who are exposed to asbestos get mesothelioma and others don’t. Early research shows that people with changes in certain genes may have a higher risk of developing mesothelioma than others when they are exposed to asbestos.

Symptoms

The symptoms of mesothelioma vary depending on whether it is in the pleura or peritoneum.

Pleural mesothelioma

The symptoms of pleural mesothelioma may include:

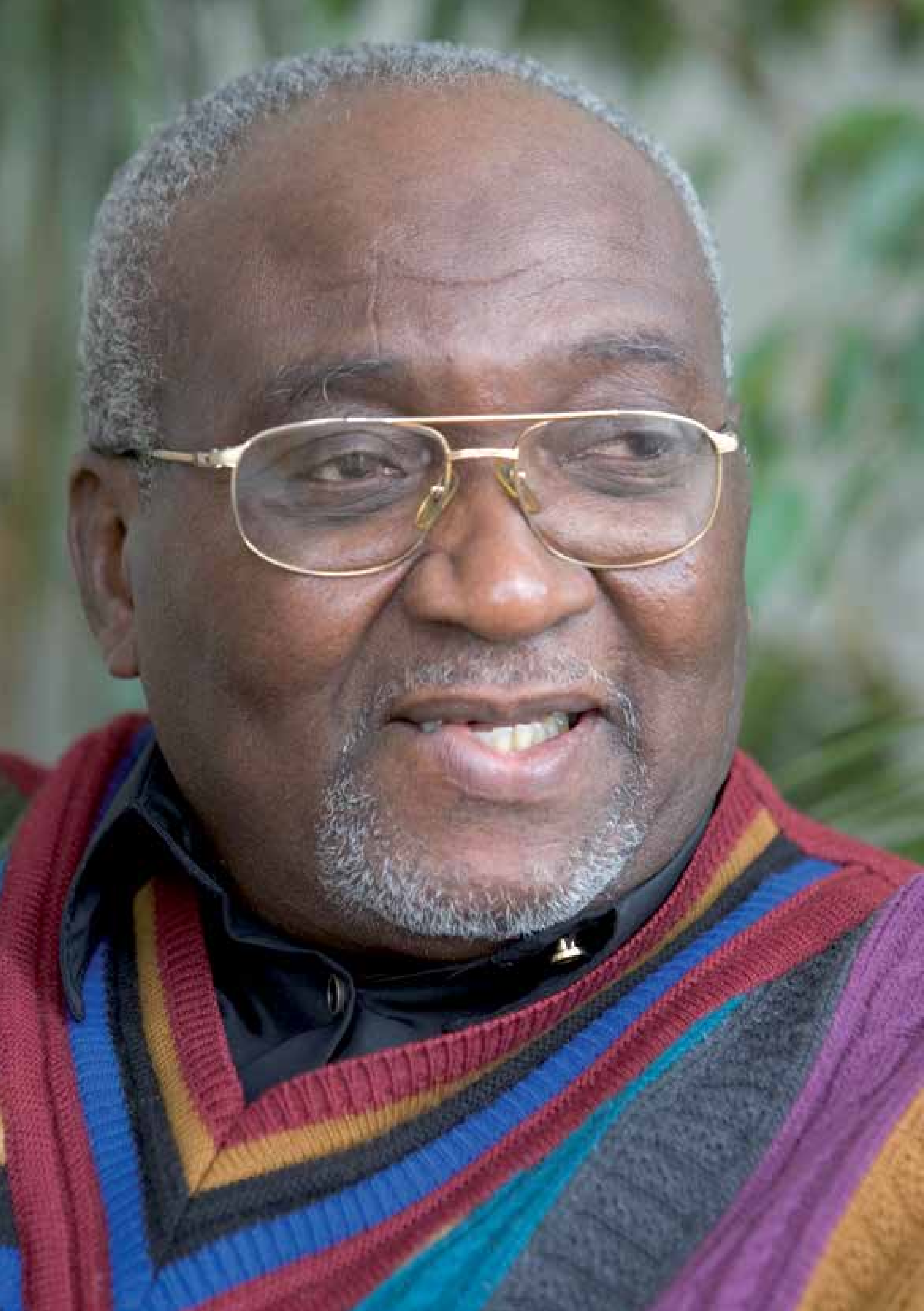
- shortness of breath
- chest pain that feels heavy, dull or aching
- a high temperature (fever)
- extreme tiredness (fatigue)
- weight loss
- loss of appetite
- a cough that does not go away
- heavy sweating at night.

Peritoneal mesothelioma

The symptoms of peritoneal mesothelioma may include:

- swelling in the tummy (abdomen)
- tummy pain
- loss of appetite
- weight loss
- feeling sick (nausea)
- changes to your normal bowel habit, for example constipation or diarrhoea – especially if you are aged over 50 and this develops for the first time.

If you have any of these symptoms, it is important to get them checked by your GP. These symptoms can be caused by conditions other than mesothelioma.



DIAGNOSING MESOTHELIOMA

How mesothelioma is diagnosed

You usually begin by seeing your GP. They will ask you about your symptoms and examine you. You may have blood tests and a chest x-ray, particularly if you have a history of asbestos exposure.

Depending on the results of any tests, your GP may refer you to hospital for further tests and specialist advice and treatment. At the hospital, the specialist will ask you about your general health and any previous medical problems.

The specialist may ask if it is possible that you have been exposed to asbestos in the past, such as in jobs you have had or places you have worked. This is called your occupational history. They may also ask if anyone in your family worked with asbestos. It usually takes a long time for mesothelioma to develop after exposure to asbestos, so you may have to think far back to your childhood or early working years.

Tests for pleural mesothelioma

Pleural mesothelioma often starts as tiny lumps (nodules) in the pleura. These will not show up on x-rays or scans until they are quite large.

If fluid has developed between the two layers of the pleura (pleural effusion), this can usually be seen easily on a chest x-ray at an earlier stage. Pleural effusions can also develop because of other cancers and some non-cancerous conditions. So you may need to have a number of different tests before your doctors can make an accurate diagnosis. Your doctor or nurse will tell you about the most suitable tests for you and what they involve.

Chest x-ray

A chest x-ray checks your lungs for anything that looks abnormal, such as thickening of the pleura or fluid around the lungs. These symptoms can be caused by conditions other than mesothelioma.

CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 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 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 is 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 will probably be able to go home as soon as the scan is over.

We have a video on our website that has more information about having a CT scan – visit **macmillan.org.uk/testsandscans**

Having a CT scan

Drainage of fluid from the pleura (pleural aspiration)

Mesothelioma cells can cause fluid to develop around the lung. This is called a pleural effusion. Your specialist doctor may take a sample of this fluid to send to the laboratory, to see if it contains mesothelioma cells. Draining the fluid may also help with your breathing.

You will usually have an ultrasound scan during the test. Ultrasound uses sound waves to build up a picture of the area. This helps guide the doctor to where the fluid is. Your doctor will give you a local anaesthetic to numb the area first. After this, they pass a needle through your skin into the fluid to take a sample.

Pleural biopsy

During a biopsy, a small piece of tissue is removed so that it can be looked at under a microscope. This can help confirm a diagnosis.

For mesothelioma, doctors usually take a piece of tissue from the thickened pleura. This is more likely to confirm the diagnosis than a sample of fluid.

We describe some of the ways your doctor may take a pleural biopsy over the next few pages.

CT or ultrasound guided biopsy

The doctor will give you a local anaesthetic to numb the area. They will use an ultrasound or CT scan to help guide them to the right place. Then, they will pass a special type of needle through your skin into the thickened area. The needle has a tip that can cut out a sample of tissue.

Thoracoscopy

This lets the doctor look at the pleura and the area around the lungs. If needed, the doctor can also take biopsies.

You will have either a general anaesthetic, or a local anaesthetic with a sedative to make you sleepy. The specialist doctor will make a small cut in your chest wall. They then put a thin, flexible tube (thoracoscope) into your chest. The tube has a light and camera at the end, so the doctors can see into your chest. They may use an ultrasound scan to guide the thoracoscope to the thickened area of pleura. Your doctor can then drain off any fluid and take a biopsy.

Sometimes doctors use a video camera with the thoracoscope. This is called video-assisted thoracoscopy (VAT). It can help doctors see the area around the lung more clearly and do complex operations if needed.

Talc pleurodesis

If your doctor drains off fluid from the pleural cavity (the space between the two layers of the pleura) during any tests, they may also do a procedure to try and stop the fluid coming back. This is called a talc pleurodesis. After the fluid is drained, they will put sterile talcum powder through the tube in your chest and into the pleural space. This helps stick the two linings together, to help stop the fluid from building up again.

EBUS and mediastinoscopy

Very occasionally, your doctor may need to take a sample from the lymph nodes in the middle of the chest (mediastinum). Doctors may be able to reach these from your windpipe using a flexible camera. This is called an endobronchial ultrasound (EBUS).

For larger biopsies, doctors may need to do a mediastinoscopy under general anaesthetic. For this, the doctor makes a small cut at the base of your throat. They then pass a thin, flexible tube (mediastinoscope) into your chest. The tube has a light and camera at the end. This shows a picture of the area on a screen, which helps the doctor see any abnormal areas. They may also take samples of the cells and lymph nodes (biopsies) to look at under a microscope.

After the biopsy

Having a biopsy can be uncomfortable but should not be painful. If you have any pain during or after the procedure, let your doctor or nurse know.

Once the doctor has taken the biopsy, they will send it to the laboratory. A doctor who specialises in examining cells (pathologist) will look at the biopsy.

Sometimes, even after taking a biopsy, the doctors may still not be sure of the diagnosis. This is because pleural mesothelioma can be difficult to tell apart from some other cancers and illnesses. If this happens, the samples may be sent to specialist laboratories to confirm the diagnosis. Sometimes you may need to have a test repeated, or you may be referred to another hospital for a second opinion.

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 on pages 129 to 133 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Tests for peritoneal mesothelioma

You may have a number of different tests to help diagnose peritoneal mesothelioma.

Abdominal x-ray

This checks for anything abnormal in your tummy area (abdomen).

CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 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 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 is 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 will probably be able to go home as soon as the scan is over.

See page 27 for a picture of a CT scanner. We also have a video on our website that has more information about having a CT scan – visit **macmillan.org.uk/testsandscans**

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, etc. 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.

Drainage of fluid from the abdomen (peritoneal aspiration)

Mesothelioma cells can cause fluid to collect in the abdomen. This is called ascites. Your doctor may take a sample of this fluid to send to the laboratory, to see if it contains mesothelioma cells.

You may have an ultrasound scan during the test. Ultrasound uses sound waves to build up a picture of the area. This helps guide the doctor to where the fluid is. Your doctor will give you a local anaesthetic to numb the area first. After this, they pass a needle through your skin into the fluid to take a sample.

Peritoneal biopsy

During a biopsy, a small piece of tissue is removed so that it can be looked at under a microscope. This can help confirm a diagnosis. Your doctor may suggest a biopsy of the peritoneum (lining that covers the organs in the tummy) to help diagnose peritoneal mesothelioma. It can be done in two ways:

- **Laparoscopy** – This procedure allows the doctor to look at other areas in your tummy (abdomen) and take more biopsies if needed. This test is done under general anaesthetic. Your doctor will make a small cut in the tummy wall. They will put a thin tube with a light and camera at the end (laparoscope) into your tummy. They can then take a small biopsy of the peritoneum.
- **CT or ultrasound guided biopsy** – The doctor will give you a local anaesthetic to numb the area. They will use an ultrasound or a CT scan (see page 32) to help guide them to the right place. Then, they will pass a special type of needle through your skin into the area they want to take a biopsy from. The needle has a tip that can cut out a sample of tissue.

After the biopsy

Having a biopsy can be uncomfortable but should not be painful. If you have any pain during or after the procedure, let your doctor or nurse know.

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Staging of mesothelioma

The stage of a cancer refers to its size and whether it has spread beyond the area of the body where it first started. Knowing the extent of the cancer helps the doctors decide on the most appropriate treatment for you.

There are a number of different staging systems. Many are based on the TNM system where:

- **T** describes the size of the cancer.
- **N** describes whether the cancer has spread to the lymph nodes and which nodes are involved. For example, N0 means that no lymph nodes are affected, while N1 means there are cancer cells in the lymph nodes.
- **M** describes whether the cancer has spread (metastasised) to another part of the body. For example, M0 means the cancer has not spread to other parts of the body, while M1 means the cancer has spread to other parts of the body.

We describe the staging systems used for pleural and peritoneal mesothelioma over the next few pages.

Pleural mesothelioma

The staging system most commonly used for pleural mesothelioma is called the International Mesothelioma Interest Group (IMIG) system. It is based on the TNM system, which has been adapted for mesothelioma.

A simplified version of the IMIG system is described here.

Stage 1 Cancer cells are only found in the inner or outer pleura in one side of the chest. The cancer has not spread to the lymph nodes or outside of the chest. Stage 1 is divided into:	
Stage 1a	Cancer cells are only found in one or more areas in the inner or outer layer of the pleura.
Stage 1b	Cancer cells have broken through the pleura into the tissue just beneath, for example to the surface of the lung.
Stage 2 The cancer is in the same areas as stage 1, but has also spread to nearby lymph nodes (N1).	

<table>
<tr><td colspan="2">Stage 3

Stage 3 is divided into:</td></tr>
<tr><td>Stage 3a</td><td>Cancer cells have spread deeper into the tissues beneath the pleura. For example:
• deeper into the tissues in the chest wall
• into, but not through, the outer lining of the heart (pericardium)
• to fatty tissue in the centre of the chest, and nearby nodes (N1).</td></tr>
<tr><td>Stage 3b</td><td>Cancer cells have spread into lymph nodes in the centre of the chest or lymph nodes further away from the lungs (N2). Or they have spread further into the chest wall, through the pericardium or to nearby organs. It may or may not have spread to lymph nodes.</td></tr>
<tr><td colspan="2">Stage 4

The cancer has spread outside of the chest to another area (metastasis or M1).</td></tr>
</table>

Peritoneal mesothelioma

There is no specific staging system for peritoneal mesothelioma. But doctors sometimes use the TNM system.

Some doctors use an adapted TNM system called the Peritoneal Cancer Index (PCI).

This looks at:

- the number of tumours in the peritoneum
- the size of the tumours
- where the tumours are in the tummy area (abdomen).

This is put together with information about whether the cancer has spread to any lymph nodes or to any areas outside of the peritoneum.

PCI is not routinely used in the UK. But you can ask your doctors for more information if you have any questions.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**. To find details about the cancer registry in your area, see page 131.


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TREATING MESOTHELIOMA

Treatment overview

Treatment for mesothelioma can include chemotherapy, radiotherapy and sometimes surgery.

Doctors are also researching whether other types of treatments called targeted therapies and immunotherapies may be helpful to treat mesothelioma. These drugs may be given as part of a clinical trial.

Pleural and peritoneal mesothelioma are treated in different ways. We have split the information about treatment into two sections, so you can read the information that is relevant to you. There is a section for treating pleural mesothelioma (see pages 50 to 65) and a section for treating peritoneal mesothelioma (see pages 66 to 69).

Some information about treatment is relevant to both types of mesothelioma. This includes information about:

- treatments to control symptoms and help you feel more comfortable (supportive or palliative care) – see pages 70 to 83
- taking part in a clinical trial – see pages 84 to 85.

How treatment is planned

If your tests show that you have mesothelioma, a team of specialists called a multidisciplinary team (MDT) will meet to plan your treatment and care. In some parts of the UK, there are specialist mesothelioma MDTs. This team will normally include:

- **chest physicians**, who are doctors experienced in lung disease (if you have pleural mesothelioma)
- **oncologists**, who are doctors experienced in using chemotherapy and radiotherapy to treat mesothelioma
- **surgeons**, who are experienced in chest surgery (if you have pleural mesothelioma) or abdominal surgery (if you have peritoneal mesothelioma)
- **specialist nurses**, who give information and support
- **palliative care nurse specialists**, who are experts in controlling symptoms
- **radiologists**, who help analyse scans and x-rays
- **pathologists**, who advise on the type and extent of the cancer.

The team may also include other healthcare professionals, such as a:

- physiotherapist
- counsellor
- psychologist
- social worker
- dietitian.

The MDT will take a number of factors into account when planning your treatment and care. These include the type and stage of your mesothelioma and your general health.

Occasionally, you may be offered a choice of treatments. If this happens, make sure you have enough information about:

- the different treatments
- what is involved
- the possible side effects.

This will help you to make the right decision for you.

If you have any questions about your treatment, ask your doctor or nurse. It is a good idea to have a family member or close friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to make a list of questions before the appointment, and take notes during the appointment.

The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of the side effects that can occur. However, these can usually be controlled with medicines. Treatment can be given for different reasons and the potential benefits will vary depending upon your individual situation.

For many people with pleural or peritoneal mesothelioma, the cancer has already spread when it is first diagnosed. This means that treatment is usually given to slow the growth of the cancer. This can help with symptoms and may improve quality of life. But for some people, the treatment will have no effect on the cancer. They may get side effects from the treatment with little benefit.

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

It’s important that you ask your doctors and nurses any questions you have about your treatment. The more you understand about your treatment, the easier it will be for you and them.

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.

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.

Treatment for pleural mesothelioma

Treatment overview

For most people, treatment is given to help control symptoms and to slow the growth of the pleural mesothelioma.

Treatments may include chemotherapy, radiotherapy and other treatments, sometimes known as supportive therapies.

Very occasionally, if mesothelioma is diagnosed before it has spread or if it has only spread to nearby tissues, surgery may be an option. This is not common as mesothelioma has usually spread before diagnosis.

Chemotherapy for pleural mesothelioma

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs disrupt the way cancer cells grow and divide but they also affect normal cells. Your doctor may offer chemotherapy to help slow the growth of pleural mesothelioma.

Although chemotherapy will not usually cure pleural mesothelioma, it can help to shrink it. It may also help with symptoms such as pain and breathlessness, and may help some people to live longer. Your doctor will let you know if chemotherapy is suitable for you.

How chemotherapy is given

Chemotherapy drugs for pleural mesothelioma are usually given by injection into a vein (intravenously).

Chemotherapy is usually given as a session of treatment. Each session of treatment may last between one and a few days. This is followed by a rest period of a few weeks. The treatment and the rest period make up a cycle of treatment. The number of cycles you have will depend on the stage of the cancer and how well it is responding to treatment.

Having chemotherapy

The drugs that are used

The most commonly used drugs to treat pleural mesothelioma are pemetrexed (Alimta®) together with cisplatin (or sometimes carboplatin). You usually have these drugs as an outpatient on the same day. You will then have a rest period with no chemotherapy for 20 days before starting your next cycle of treatment. If you have pemetrexed, you will be given vitamin B12, folic acid and steroids. These help to reduce the side effects of the treatment.

Other chemotherapy drugs may sometimes be used. These may be given as part of a clinical trial.

We have more information about chemotherapy and the drugs mentioned on our website (**macmillan.org.uk**).

Side effects of chemotherapy

Chemotherapy can cause side effects. These can often be managed with drugs and usually improve after treatment has finished. Different drugs cause different side effects. Your cancer doctor or nurse will explain what to expect based on the treatment you will have.

We explain the most common side effects of pemetrexed and cisplatin here, as well as some ways to reduce or control them. You may get some of the side effects we mention, but you are very unlikely to get all of them.

Always tell your cancer doctor or nurse about any side effects you have.

Risk of infection

Chemotherapy can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more chemotherapy. If your white blood cell count is 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 that you can't explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is 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 blood cells. This is called a blood transfusion.

Feeling sick

You may feel sick in the first few days after chemotherapy. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Some types of anti-sickness drugs can sometimes cause constipation. If you notice this, contact your doctor or nurse for advice.

Sore mouth

You may get a sore mouth or mouth ulcers. This can make you more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Diarrhoea

If you have diarrhoea, contact the hospital for advice. Try to drink at least two litres (three and a half pints) of fluids every day. It can help to avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment affects the nerves, which can cause numb, tingling or painful hands or feet. You may 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 for some people they may never go away. These may start after treatment finishes. Talk to your doctor if you are worried about this.

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

Eye problems

Your eyes may become sore and inflamed (conjunctivitis) or produce more tears. Tell your doctor if this happens. They can give you eye drops to help.

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.

Hair loss

Your hair may get thinner but you are unlikely to lose all the hair from your head. Hair loss usually starts after your first or second treatment. It is almost always temporary and your hair will usually grow back after treatment ends. Your nurse can talk to you about ways to cope with hair loss.

We have more information about side effects and how to cope with them:

- Visit **macmillan.org.uk/sideeffects** to read the information online.
- Visit **be.macmillan.org.uk/sideeffects** to order free information.
- Watch our videos about side effects at **macmillan.org.uk/cancerinformationvideos**

Radiotherapy for pleural mesothelioma

Radiotherapy uses high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is normally given as a series of short, daily outpatient treatments in the radiotherapy department. Radiotherapy for mesothelioma may be given:

- to help relieve symptoms, such as pain and breathlessness
- occasionally alongside surgery and chemotherapy as part of a clinical trial (see pages 84 to 85).

Sometimes you may only need one or two treatments. Or you may need a course of treatment over a few days or weeks.

Radiotherapy for mesothelioma does not make you radioactive and it is perfectly safe for you to be with other people, including children, throughout your treatment.

> ‘My chest started to get very tight and thick with phlegm. I had radiotherapy and that stopped the phlegm coming up to my chest, which helped me breathe better.’
>
> **Martin**

Planning your radiotherapy

Before you start your treatment, radiotherapy has to be carefully planned. This helps to make sure it is as effective as possible, whilst causing the least possible damage to the healthy tissue nearby. It is planned by a cancer specialist (clinical oncologist), a physicist and a specialist radiographer.

Your first planning visit will take about 30 to 60 minutes. You may have more than one planning visit. The staff in the radiotherapy department will explain what to expect. It is important that you feel you are involved in your treatment. Remember to ask questions about anything you do not understand or feel worried about.

You will usually have a CT (computerised tomography) scan, which takes x-rays of the area to be treated. You may need some small marks drawn on your skin. These help the radiographer (who gives you your treatment) position you accurately and show where the treatment will be given. It is important not to rub them off until your course of treatment has finished. Sometimes tiny, permanent marks are made on the skin.

Treatment sessions

The radiographer will tell you how long each treatment session will take before you start. It usually only lasts a few minutes. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

At the beginning of each treatment session, the radiographer will position you carefully on the couch and make sure you are comfortable. Once you are in the correct position, the radiographers will leave the room and you will be given your treatment. They will be able to see you during your treatment. Treatment rooms have an intercom so the radiographers can talk to you as well.

Side effects of radiotherapy

You may develop side effects while you are having your radiotherapy treatment and for some time afterwards. These usually improve gradually over a few weeks or months after treatment finishes. Your doctor, radiographer or nurse will let you know what to expect. Tell them about any side effects you have during or after treatment. There are often things that can be done to help.

These side effects should improve gradually once your course of treatment is over, but it is important to let your doctor know if they continue.

Tiredness (fatigue)

Many people feel tired during radiotherapy. Tiredness can continue for some days or weeks after finishing your treatment. If you feel tired, it is important to get plenty of rest. But it is a good idea to balance this with some gentle exercise, such as short walks. This will help give you more energy and keep your muscles working. Make sure you save some energy for doing the things you enjoy. Ask others for help with tasks, such as chores, if these are tiring you out.

Skin reactions

Some people develop a skin reaction while having radiotherapy. How your skin reacts will depend on the amount of radiotherapy you are having. Your doctor, radiographer or nurse will tell you how to look after your skin during and after treatment.

Difficulty swallowing

After a week or two of treatment, you may find you have some difficulty with swallowing. You may also have heartburn and indigestion. This happens because radiotherapy to the chest can cause inflammation in the tube that runs from your mouth to your stomach (called the gullet or oesophagus).

Tell your doctors if you have problems swallowing. They can give you medicines to help. If you don’t feel like eating, or have problems with swallowing, talk to your doctor or a dietitian. They may recommend you have some high-calorie drinks to help. You can get these from most chemists, and your GP can give these to you.

Cough

You may develop a cough during or after radiotherapy. This usually settles within a few weeks of finishing your treatment. Always tell your doctor, radiographer or specialist nurse if:

- the cough does not get better
- you develop a temperature or become short of breath, as you may have an infection.

Feeling sick

Some people find that their treatment makes them feel sick (nausea) and be sick (vomit). Tell your doctor if this happens. They can give you anti-sickness drugs (anti-emetics) to help.

We have more information about side effects and how to cope with them:

- Visit **macmillan.org.uk/sideeffects** to read the information online.
- Visit **be.macmillan.org.uk/sideeffects** to order free information.
- Watch our videos about side effects at **macmillan.org.uk/cancerinformationvideos**

Surgery for pleural mesothelioma

Surgery for pleural mesothelioma is usually done to either diagnose the cancer or to help relieve symptoms.

Surgery to try to cure pleural mesothelioma or help people live longer is called radical surgery. Radical surgery is only possible in a very small number of people. This is mainly because mesothelioma is often found at an advanced stage. Because it is major surgery, you also need to be well enough to have the surgery.

These major operations are done by specialist chest (thoracic) surgeons who are experienced in treating mesothelioma. Sometimes it may be done as part of a clinical trial (see pages 84 to 85).

Removing part or all of the pleura

This is when the surgeon removes only the pleura that contains mesothelioma cells. They do not remove any lung tissue. Removing the outer pleura is called a pleurectomy. Removing the inner pleura is called a decortication. Depending on the stage of mesothelioma, you may have both of these operations together. This operation is called a pleurectomy decortication, or PD.

Surgeons sometimes do a smaller operation to remove only some of the pleura (partial pleurectomy). This can help with symptoms, for example to help reduce the build-up of fluid in the pleura (pleural effusion).

It may be possible to have the partial pleurectomy under keyhole surgery. During this operation, the surgeon makes several small openings instead of one large cut. The other types of surgery are usually performed through one large cut on the side and back of the chest (thoracotomy).

Removing the pleura and nearby areas

For more advanced mesothelioma, as well as removing the pleura, the surgeon may also have to remove other nearby areas. These can include part of the covering of the heart (pericardium), lung tissue and the muscle between the lung and the abdomen (diaphragm). This is known as an extended pleurectomy decortication (EPD).

If surgery is a suitable treatment for you, your specialist will tell you more about what to expect.

Treatment for peritoneal mesothelioma

Treatment overview

For most people, treatment is given to help control symptoms and to slow the growth of peritoneal mesothelioma.

Treatment may include chemotherapy and other treatments, sometimes known as supportive therapies.

Very occasionally surgery, possibly with chemotherapy, may be an option.

Chemotherapy for peritoneal mesothelioma

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs disrupt the way cancer cells grow and divide but they also affect normal cells.

Your doctor may offer you chemotherapy to help slow the growth of peritoneal mesothelioma and control symptoms. Your doctor will let you know if chemotherapy is suitable for you.

How chemotherapy is given

Chemotherapy drugs for peritoneal mesothelioma are usually given by injection into a vein (intravenously). Chemotherapy is usually given as a session of treatment. Each session of treatment may last between one and a few days. This is followed by a rest period of a few weeks. The treatment and the rest period make up a cycle of treatment. The number of cycles you have will depend on the stage of the cancer and how well it is responding to treatment.

The drugs that are used

The most commonly used drugs to treat peritoneal mesothelioma are pemetrexed (Alimta®) together with cisplatin (or sometimes carboplatin). You usually have these drugs as an outpatient on the same day. You will then have a rest period with no chemotherapy for 20 days before starting your next cycle of treatment. If you have pemetrexed, you will be given vitamin B12, folic acid and steroids. These help to reduce the side effects of the treatment.

Other chemotherapy drugs may sometimes be used. These may be given as part of a clinical trial.

We have more information about chemotherapy and the drugs mentioned on our website (**macmillan.org.uk**).

The most common side effects of pemetrexed and cisplatin are described on pages 52 to 57.

Chemotherapy into the abdomen (HIPEC)

If you are having surgery for peritoneal mesothelioma (see opposite page), your doctor may suggest having chemotherapy into the tummy (abdomen) during the surgery. This is called HIPEC (hyperthermic intraperitoneal chemotherapy).

This treatment is usually only suitable for a small number of people. This is because you need to be well enough for the surgery.

During the operation, the surgeon will remove all or most of the tumours. They will wash out the area to remove any loose mesothelioma cells, and then put chemotherapy into the tummy. The chemotherapy drug used is usually cisplatin. Sometimes other chemotherapy drugs may be used if you are taking part in a trial.

The chemotherapy is gently heated before being put in your tummy. This can help it work better for this type of cancer. The chemotherapy is left in place for around 60 to 90 minutes to give it time to work. It is then washed out.

The side effects of giving chemotherapy this way can be different to chemotherapy into the vein. Your doctor or nurse will explain what to expect.

Surgery for peritoneal mesothelioma

Surgery is only suitable for a small number of people with peritoneal mesothelioma. The mesothelioma needs to be at a very early stage and you need to be well enough to have the surgery.

The surgeon will remove most of your peritoneum (peritonectomy). They may also have to remove affected nearby organs. These may include the spleen, the gall bladder and sometimes part of the bowel. Women may also need to have the womb and the ovaries removed.

If you need part of the bowel removed, you may need to have a bag fitted on your tummy to collect your poo (stools). This is known as a stoma. The stoma may be temporary or permanent, depending on the situation.

When they have removed all or most of the tumours, they may put a heated chemotherapy drug into your tummy. This is called hyperthermic intraperitoneal chemotherapy (HIPEC) – see opposite page.

The operation will be done by a specialist abdominal surgeon who is experienced in the treating peritoneal mesothelioma. You will need to travel to a specialist centre for this surgery.

If your specialist offers you surgery, they will give you more information about what to expect.

Controlling symptoms

For people with mesothelioma, the main aim of treatment is to control symptoms.

There are many different treatments that can help to control the symptoms of pleural and peritoneal mesothelioma.

There are also many different people who can help you manage your symptoms, including your:

- hospital consultant
- nurse specialist
- GP.

They may suggest referring you to a palliative care team. These teams specialise in managing symptoms and giving emotional support to you and your family. Many palliative care teams have specialist nurses who can visit you at home.

Treatments to control symptoms of pleural mesothelioma

Breathlessness

Breathlessness is a common symptom of pleural mesothelioma. It is often caused by a build-up of the fluid between the two layers of the pleura (the membranes that cover the lungs). This is called a pleural effusion.

Treating fluid on the lung (pleural effusion)

To treat a pleural effusion, doctors place a small tube between the two layers of the pleura to drain off the fluid. The doctor will give you a local anaesthetic to numb the area first. They will then gently insert the tube, usually in the side of your chest.

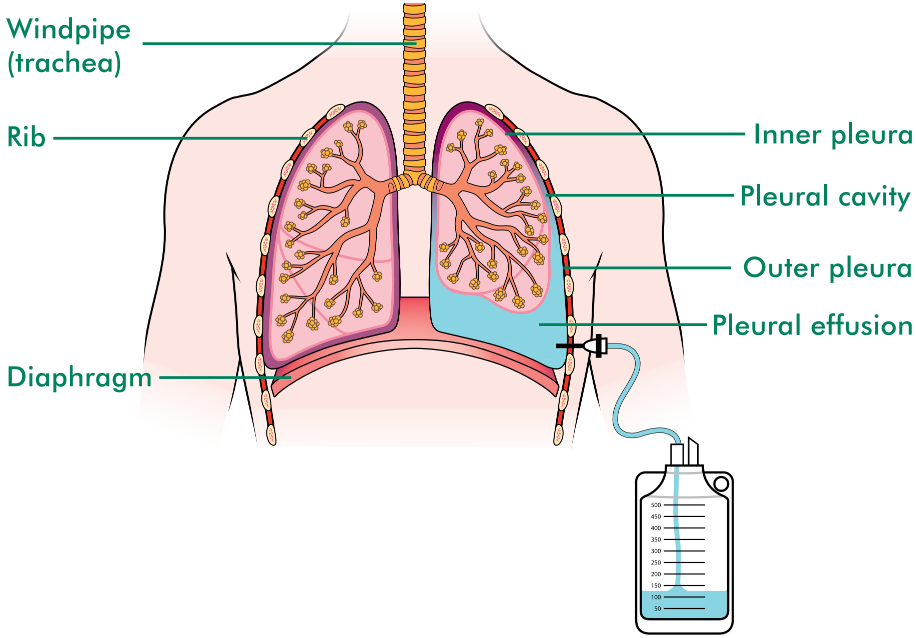
When the tube is in place, they will connect it to a bag or a bottle which collects the fluid. The tube usually stays in for a couple of days or longer. The fluid can build up again once the tube is taken out, so you may need to have it drained more than once.

Your doctor may recommend a procedure to help prevent the fluid building up again. This is called a talc pleurodesis. Doctors usually do a talc pleurodesis at the same time as draining the fluid. Once the fluid has been drained off, the doctor puts sterile talcum powder through the tube into your chest. It helps to stick the two layers together to prevent the fluid coming back. Talc pleurodesis is sometimes done during a video-assisted thoracoscopy. Your doctor will be able to tell you more about this.

Another option is to have a drain put in which can stay in place for a longer period of time. This may be suitable if you cannot have talc pleurodesis. Doctors place one end of a soft, flexible tube in the space where the fluid collects. They then position the other end of it under the skin in the chest. It can stay in place so that fluid can be drained off whenever needed. The end of the tube is covered with a dressing when you are not using it.

You may have this type of drain put in as a day patient (day-case procedure). Or you may need to stay in hospital for a few days. The nurses can show you how to drain the fluid yourself if you feel comfortable with this. Or they can arrange for a district or community nurse to do it instead.

A pleural effusion with drainage



We have more information about pleural effusion on our website (**macmillan.org.uk**).

Managing breathlessness

There are things you can do to help manage breathlessness. These include breathing techniques, relaxation and coping strategies. They can all help to reduce the distress of breathlessness and make your breathing easier.

Even simple things, such as how you position yourself when sitting or standing, can be helpful. Using a fan or sitting by an open window with cool air blowing on to your face may also help ease breathlessness.

Your doctor may give you medicines to help with breathlessness. This may be a low dose of the painkiller morphine, or drugs to help relieve the anxiety and panic that breathlessness can cause. Some people may benefit from using oxygen at home. Your doctor or palliative care nurse can organise for you to have oxygen at home if it is suitable for you.

> ‘After I came out of hospital, I started doing breathing and relaxation exercises to help with my lung capacity. I also went for short walks and gradually built it up. Eventually, I joined a walking club. I struggled at first, but I’ve kept it up!’
>
> **Amir**

Cough

Coughing is also a common symptom of mesothelioma. This can be difficult to cope with as it can sometimes cause other symptoms, such as pain, vomiting and tiredness.

Your doctor may be able to give you medicines such as a low dose of morphine painkiller to help. You may also find it helpful to:

- sleep in a different position – maybe propped up with pillows
- use steam inhalations or saline nebulisers – a nebuliser is a small machine that turns saline into a fine mist, so you can breathe it deep into your lungs.

Treatments to control symptoms of peritoneal mesothelioma

Ascites

Peritoneal mesothelioma can cause a build-up of fluid in the tummy (abdomen). This is known as ascites. Your tummy becomes swollen and you may have pain, and feel sick and breathless.

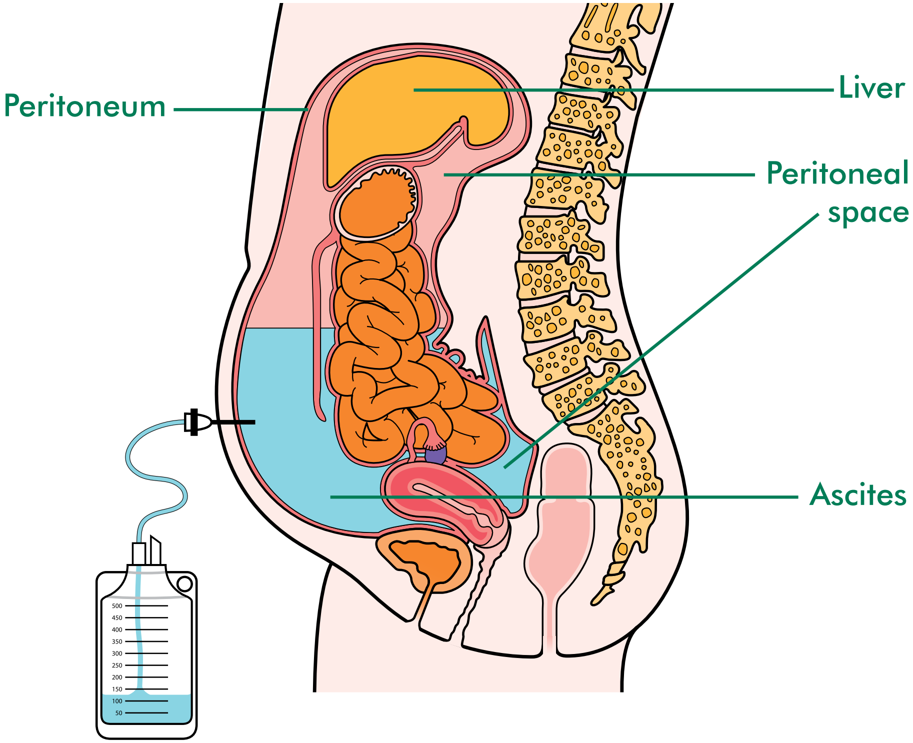
Doctors can treat ascites by putting in a small tube to drain off the fluid from your tummy. This helps to relieve the symptoms. They will give you a local anaesthetic in your tummy to numb the area first. The doctor then makes a small cut in the skin and gently inserts the tube. They attach the tube to a drainage bag to collect the fluid. The tube may be held in place with a couple of stitches and covered with a dressing.

How long the tube needs to stay in for depends on the amount of fluid that needs to be drained. It may be in for a couple of days or longer. Sometimes, a small amount of fluid can be drained in the outpatient clinic. If there is a large amount of fluid, you may need to stay in hospital.

It is possible for the fluid to build up again, so you may need the fluid drained off more than once. If it builds up again quickly, your doctor may put a tube into your tummy which can be left in place. When the fluid starts to build up, it can be attached to a drainage bottle and drained off. The end of the tube is covered with a dressing when you are not using it. Your doctor will be able to give you more information about this.

Your doctor may also prescribe a tablet called spironolactone. This is a water tablet (diuretic), which makes you wee (pass urine) more often. It may help stop the fluid building up in the tummy.

Side view of the tummy (abdomen) showing draining of ascites



Managing bowel obstruction

Occasionally, peritoneal mesothelioma may cause the bowel to block. Symptoms may include:

- pain
- tummy bloating
- sickness
- constipation.

If this happens, tell you doctor straight away. They will give you medicines to control your symptoms. They may also suggest treatments that will help rest your bowel for a while and help with the blockage.

Treatments to control other symptoms of mesothelioma

Pain

Pain is a common symptom of mesothelioma. Let your doctors or specialist nurse know if you have pain so that they can treat it early on.

Painkillers

There are many painkilling drugs available to treat different types and levels of pain. They include:

- painkillers, such as paracetamol, codeine or morphine
- anti-inflammatory drugs, such as ibuprofen (Brufen®) and diclofenac (Voltarol®)
- other types of medication, such as steroids or patches to help numb pain.

Some people have nerve pain, which happens when the mesothelioma presses on nerves. This type of pain is best treated with painkillers such as:

- gabapentin
- pregabalin (Lyrica®)
- amitriptyline.

You may need a combination of painkillers to get the best pain control. It can be helpful to keep note of the painkillers you take, and when you have taken them.

Other ways to control pain

Other ways of relaxing and helping to reduce pain include:

- listening to relaxation CDs
- having a long soak in a warm bath
- having a massage to an area of your body that is not painful, such as your hand or foot.

Occasionally, if your pain is troublesome, your doctor or nurse may suggest a short stay in hospital or a hospice to get your pain under control. They may also refer you to a doctor who specialises in pain control, or to a pain clinic. If you have nerve pain that has been more difficult to control, they may suggest other methods of pain control. This may include a specialised procedure called a nerve block.

Night sweats

Mesothelioma can cause some people to sweat a lot at night. This can be distressing, especially if you wake up at night with damp pyjamas and bedding. Let your doctor know if this happens as they may be able to give you medicines to help. You may also find the following tips helpful:

- Try to avoid drinks that contain caffeine before you go to bed or in the night.
- Keep the room temperature cool or use a fan.
- Avoid using duvets or blankets that make you too hot.
- Lie on a towel so that you avoid getting your bedding damp.
- Use cotton sheets and pyjamas, and have some spare so that you can change them in the night if you need to.

Loss of appetite

Mesothelioma and some cancer treatments can cause problems with eating and digestion. If your appetite is poor, try having smaller, more frequent meals. You can also add high-protein powders to your normal food. Or you can boost your meals with nutritious, high-calorie drinks. These are available from most chemists or your GP can give these to you.

If you have lost your appetite, medicines such as steroids may help. You can also ask your GP or nurse to refer you to a dietitian at your hospital. They can advise you on which foods are best for you and whether any food supplements would help. If you are at home, your GP can arrange this for you.

> ‘The dietetics team advised me to use food supplements. This gave me the confidence to try new things because I knew that if they didn’t work, then I was still getting the nutrients from the supplements.’
>
> **Joshua**

Tiredness

Many people with mesothelioma feel tired and have less energy to do the things they normally do. This may be due to the illness or it may be a side effect of treatment. It is important not to do too much. You may need to rest more than usual, but it is important not to stop doing things completely. Try to balance rest with gentle exercise, such as walking.

Some people find it helpful to set goals to help them plan their daily activities. These goals may include:

- cooking a light meal
- going for a short walk
- meeting a friend.

Some causes of tiredness can be treated, for example anaemia (low red blood cells). Your doctor can take a blood sample from you to check if you have anaemia. You may need a blood transfusion if you are very anaemic.

If sleep problems are causing you to feel more tired, then getting better sleep can help how you feel. You can read about ways of improving your sleep in our information about difficulty sleeping – visit **macmillan.org.uk/difficultysleeping**

Tiredness is also a common symptom of depression. If you think you are depressed, talk to your doctor or nurse. You and your doctor will be able to work out if what you are feeling is depression or fatigue. Talking about your feelings with a professional counsellor can often help depression.

Complementary therapies

Some people feel that complementary therapies, such as acupuncture, massage, aromatherapy and relaxation techniques, are helpful. Many hospitals and hospices offer these therapies.

If you would like to try a complementary therapy, check with your cancer specialist or GP first. This is important because some complementary therapies should be avoided during, and for a short time after, cancer treatments.

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 if you would like 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.

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail.

There are currently a number of clinical trials for mesothelioma. Mesothelioma UK has a list of current trials (see page 130 for contact details). There are different criteria for being able to enter a clinical trial. Your doctor or nurse can explain more about this to you.

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.

AFTER YOUR TREATMENT

Follow-up

After your treatment has finished, your hospital doctor, GP or specialist nurse will arrange for you to have regular check-ups. They will continue to monitor your symptoms and check if you need any more treatments to help control them. If you have any problems or notice any new symptoms between check-ups, let your doctor know as soon as possible.

If you think you need extra help at home, tell the doctors or nurses looking after you. They can look at your needs and organise extra support. They can also arrange for you to see a physiotherapist if you need help with your mobility or advice on breathing exercises.

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. These may include meals on wheels, a home helper or money to help with hospital transport 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.

Mesothelioma UK provide specialist information and support to people with mesothelioma. You can call their helpline for free on **0800 169 2409** (Monday to Friday, 8.30am to 4.30pm).

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.

> 'I spoke to a Macmillan nurse about Dad's condition. I asked about support groups and what to expect with chemotherapy, and all those other questions we think we'll never have to ask.'
>
> **Emmeline**


ROCHA. JOHN ROCHA

YOUR FEELINGS AND RELATIONSHIPS

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. Most of the time, it's impossible to know exactly what has caused a person's cancer. 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.

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.

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 and teenagers when an adult has cancer** includes discussions about sensitive topics. There's also a video on our website that may help, at **macmillan.org.uk/talkingtochildren**

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.

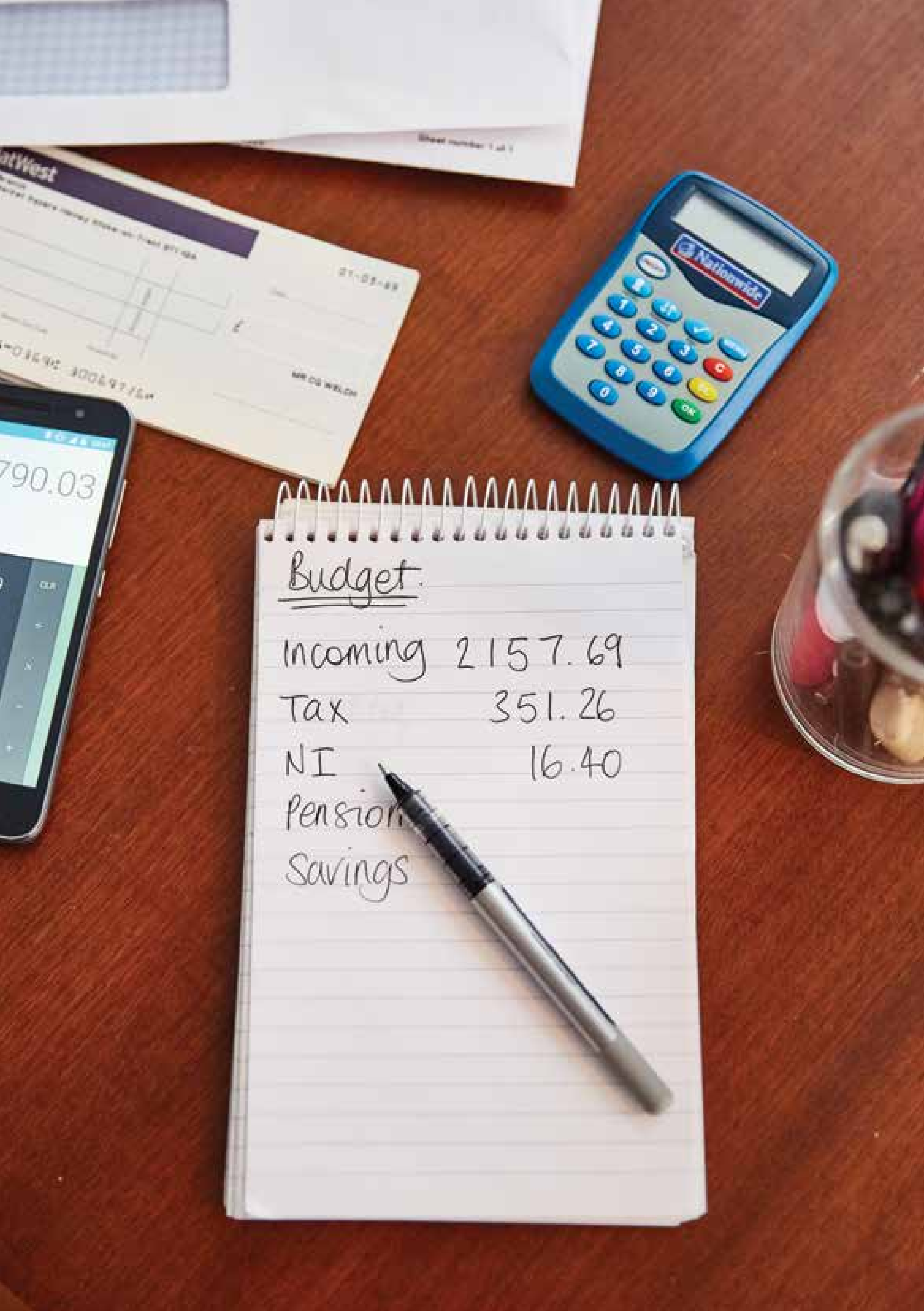
There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

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.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MR CG WELCH

FINANCIAL HELP AND WORK

Financial help and benefits

Most people who have been diagnosed with mesothelioma are able to receive financial help. There are two main ways of receiving financial help:

- getting benefits paid by the Department for Work and Pensions (DWP)
- getting compensation from your employer, former employer, or another person or organisation responsible for your exposure to asbestos.

Benefits

People often think that benefits paid by the government are means-tested (dependent on your savings and income). It is important to remember that although some benefits are means-tested, others are not. A benefits adviser or a solicitor will be able to tell you more about which benefits you can claim.

It is a good idea to get advice from a specialist solicitor before claiming benefits. Some benefits, such as Industrial Injuries Disablement Benefit and claims for lump sums (see pages 102 to 103), need you to give information about your work history and exposure to asbestos dust. It is important that the information you give for this is the same as the information you give in any compensation claim you make.

You can also get more information from our Welfare Rights Advisers by calling our support line on **0808 808 00 00**. Local asbestos support groups may also be able to offer you advice and information about benefits. You can get information about support groups from Asbestos Victims Support Group Forum UK and Mesothelioma UK – see pages 129 to 130 for contact details.

Statutory Sick Pay and Employment and Support Allowance

If you are employed but unable to work because of illness or disability, you may be able to get Statutory Sick Pay (SSP). Your employer will pay SSP for up to 28 weeks of sickness. Before SSP ends, find out whether you can get a benefit called Employment and Support Allowance (ESA). ESA also provides some support to those who can do some work.

There are two types of ESA:

- **contribution-based** – 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.

People may get only one type or both.

In England, Scotland and Wales, income-related ESA is gradually being replaced by a new benefit called Universal Credit. It has been introduced in Northern Ireland in stages since September 2017. Contribution-based ESA is staying the same. The benefit you have to apply for will depend on where you live. Call our support line on **0808 808 00 00** to speak to a Welfare Rights Adviser. They can tell you how these changes may affect you.

Personal Independence Payment and Attendance Allowance

These benefits are for people who have difficulty walking or looking after themselves. Personal Independence Payment (PIP) is for people aged 16 to 64. As part of the welfare reforms, PIP has replaced the Disability Living Allowance (DLA) for everyone making a new claim in the UK.

In all countries in the UK, Attendance Allowance (AA) is for people over the age of 65.

There are special rules for people who are terminally ill and applying for PIP or AA. Under these rules, the claim is given priority. This means it will be dealt with more quickly. You will also receive the benefit at the highest rate.

Industrial Injuries Disablement Benefit

This is an important benefit that is payable to people with certain asbestos-related illnesses, including mesothelioma. It is not means-tested and is payable in situations where the illness may have been caused by exposure to asbestos dust at work. It is not necessary for a person to have worked with asbestos to get this benefit. They only need to have been exposed to asbestos dust at work. You cannot get this benefit if you were self-employed in the work that led to the exposure.

Industrial Injuries Disablement Benefit can be paid weekly, every 4 weeks or every 13 weeks into your bank account. People with mesothelioma are entitled to the maximum rate. If you are given this benefit, you may also be entitled to other benefits. You can get more information about these from a benefits adviser or specialist solicitor.

Lump-sum payments

You may be able to get a one-off, lump-sum payment. There are different types of payment. Which ones you can apply for depends on what other benefits you are entitled to.

The Pneumoconiosis etc (Workers' Compensation) Act 1979

You may be entitled to a lump-sum payment under this act if you have been awarded Industrial Injuries Disablement Benefit. You can claim this payment:

- whether or not you are likely to be able to make a claim against the employer you were working for when you were exposed to asbestos dust
- if the employer is no longer in business
- if you have not already settled a compensation claim.

Even if you are likely to get compensation from the employer's insurers, it is still worth making a claim for this benefit. This is because you may receive a payment within weeks of making the application. You must claim within one year of the award for Industrial Injuries Disablement Benefit being made.

Diffuse mesothelioma payments (2008 scheme)

This scheme is for people who cannot claim either the Industrial Injuries Disablement Benefit or the benefit under the Pneumoconiosis etc (Workers' Compensation) Act 1979.

Usually, this is because their exposure to asbestos was not as a result of their work as an employee. This can include people:

- who came into contact with asbestos from a relative (for example, by washing their clothes that were contaminated with asbestos dust)
- who were exposed while self-employed.

Payment is made as a one-off, lump sum. The claim must be made within a year of being diagnosed with mesothelioma. You will be asked to provide information about your illness, which is available from your doctor.

Diffuse Mesothelioma Payment Scheme (DMPS)

This scheme provides payments for people who were diagnosed with mesothelioma on or after 25th July 2012. It is only for people who were exposed to asbestos at work and are unable to find the employer, or the employer's insurer. The scheme can also pay out to eligible relatives or dependants of a person who has died from mesothelioma.

You can still claim under this scheme even if you have already claimed under the 2008 scheme or the Pneumoconiosis etc (Workers' Compensation) Act 1979. If you already have a payment from one of these schemes, it will be deducted from any DMPS payment you get. Even if you have not been successful in claiming under other schemes, you may still be eligible for the DMPS scheme.

It is very important to get advice from a specialist solicitor before making this type of claim. This is because the possibility of claiming from a former employer (or their insurer) must be fully investigated first. If this has not been done, the claim will be rejected. The information given supporting the claim may affect a later claim against the former employer or their insurers.

For more information about the 2008 scheme and the DMPS, visit **gov.uk/diffuse-mesothelioma-payment**

Help for people who were in the armed forces

If you were in the armed forces and you have mesothelioma because you came into contact with asbestos, you may be able to make a claim with your local Veterans Advisory and Pensions Committee. Call the Veterans UK helpline on **0808 1914 218** for more information.

Compensation from employers

Anyone diagnosed with mesothelioma who has worked somewhere where they were exposed to asbestos in the past may be able to claim compensation from their employer. This includes people working in the armed forces who have been exposed to asbestos after 1987.

This type of compensation claim requires specialist legal knowledge and must be made through an experienced, specialist solicitor. When looking for a solicitor, it is important to look for one from a specialist team of solicitors that has experience dealing with both asbestos-related disease claims and mesothelioma claims.

It is important to know that advertisements and websites may be misleading. Before deciding on a solicitor, you may want to ask them some questions (see page 110). Don't be afraid to ask them to go over anything that you have not understood or to ask for more information.

> ‘When I was diagnosed with mesothelioma, the nurses and the doctors said that I should be looking into claiming compensation. This is because mesothelioma is generally only caused by exposure to asbestos.’
>
> **George**

There are many ways you can find a specialist solicitor:

- You can ask your specialist nurse or doctor if they have a list of specialist solicitors.
- The Association of Personal Injury Lawyers has a list of accredited specialist lawyers (see page 129).
- You can ask your local asbestos support group, as they often work closely with a panel of local specialist solicitors. You can get details of local support groups from Mesothelioma UK (see page 130).

For a compensation claim to be successful, you have to show the following:

1. It is likely that your mesothelioma is caused by exposure to asbestos. Usually, exposure will have happened during your work. But you may have been exposed in other ways. For example, you may have come in contact with the clothes of someone who was exposed to asbestos at work. More rarely, there may be other circumstances which resulted in exposure to asbestos.

   The legal standard of proof is that “on the balance of probabilities” the exposure caused the mesothelioma. This means that, although it cannot be certain that the mesothelioma was caused by exposure to asbestos, it is more likely than not that it was.

2. Your exposure happened because your employer at the time (or another person or organisation responsible) was:

   - careless (negligent) in not keeping up the standards required by law
   - not following specific safety regulations.

   An example of this is that you were exposed to asbestos during your employment when your employer knew, or should have known, of the risks to you, even if you were unaware of them.

If a former employer has gone out of business, it may be possible to claim against the employer's insurers. If they cannot be found, it may be possible to make a claim under the Diffuse Mesothelioma Payment Scheme (see pages 104 to 105).

Claims must be started within 3 years of the date you were first diagnosed with an injury due to asbestos. This means 3 years from the date of diagnosis of an asbestos-related illness, not 3 years since exposure to the asbestos. In Scotland, the claim must be taken to court within 3 years or it will be stopped (time-barred). Sometimes this time limit can be extended, so ask for advice even if you think it may be too late.

Questions to ask a solicitor

Below are some important questions you can ask a solicitor, to make sure they are suitable for your situation.

- Is the solicitor a Fellow of the Association of Personal Injury Lawyers (APIL)?
- Does the solicitor specialise in mesothelioma and asbestos-related disease cases?
- How many asbestos cases has the solicitor handled in the last three years?
- How many of these have been dealt with at a court hearing?
- Will the solicitor provide you with a free initial consultation?
- Will they visit you at home, if necessary?
- Will the solicitor provide you with a free summary of what will be involved in making your claim?
- Will they work on a ‘no win, no fee’ basis?
- Will the solicitor obtain an insurance policy to cover legal fees?
- Will the solicitor take a percentage of your compensation?
- Will you be expected to pay expenses, such as medical report costs and court fees, in advance?
- How will you be kept informed of what is happening with your claim?
- How long will the claims process take?
- How soon does the solicitor expect to start a court action?

You can use the notes page opposite to write down any answers you receive.

Costs of claiming compensation

Making a personal injury compensation claim in England and Wales should not cost you any money. Any specialist solicitors should offer a free initial consultation and to deal with your claim on a 'no win, no fee' basis. They will also come to visit you at home, if needed. Make sure you discuss with the solicitor the options for funding, before any claim is started.

If you are a member of a trade union or a professional association, or you have legal expenses insurance cover, let your solicitor know.

If your solicitor is prepared to take your case on a 'no win, no fee' basis, then they will arrange insurance to protect you against the risk of having to pay the defendant's (usually your former employer's) legal costs. Insurance should also cover the other expenses that have to be paid to make your claim, such as a fee to the medical expert for a report.

Payment of the insurance premium should be delayed until the case is finished. Ask your solicitor about this payment. If your case is successful, the insurance will be paid by the other party. Most specialist solicitors offer arrangements where the insurance covers the cost of the premiums if the claim is unsuccessful. This means that in that situation, there is no charge for the premium.

In Scotland and Northern Ireland, people making a claim may be entitled to legal aid. But if insurance is available, the premium will not be repaid, even if the claim is successful. The entitlement to legal aid may be subject to a contribution. The amount will depend on a person's financial situation.

> 'My solicitor is a specialist in industrial disease claims and he's very understanding. He knows that he can't talk to me for too long because I get tired, so we've spoken a lot by email.'
>
> **Liam**

Work

Whether you feel able to go back to work depends on how well you feel. It will also depend on what kind of treatment you have had, and how well the doctors expect it to work. It is important to do what is right for you. 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. Some people may wish to take early retirement because of their health.

We have more information about going back to work:

- Visit **macmillan.org.uk/work** to read the information online.
- Visit **be.macmillan.org.uk/work** to order free information.
- Call us on **0808 808 00 00** to order the information you need.

Insurance

After having cancer treatment, it can be more difficult to get certain types of insurance, including life and travel insurance. An Independent Financial Adviser (IFA) can help you look at your financial needs and find the best deal for you.

Our booklet **Insurance** has more information about getting health, life, travel and car insurance. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00** to order a free copy.

You may also like to join the travel insurance group on our Online Community, where you can share your experiences of getting insurance and talk to others in a similar situation to you. Visit **community.macmillan.org.uk/cancer_experiences/travel_insurance**

INFORMATION FOR CARERS

Looking after yourself

If you are a relative or friend of someone who has mesothelioma, you may be caring for them. You may help with their everyday needs, such as:

- cooking meals
- helping around the house
- helping them with washing and bathing.

While you may be very happy to do this, there may come a time when you might need some extra support. There are a number of health and social care professionals who can provide support for both you and the person you are caring for. Let your GP or nurse know if you need extra support. Caring for someone you love can be physically and emotionally difficult. If you have been looking after them for some time, you may start to feel tired. Let your GP or nurse know so that they can make sure that you both get the support you need.

It is important to look after yourself too. Remember that having some support and help can allow you to regain your previous relationship with the person with cancer.

If your relative or friend is making a compensation claim (see pages 106 to 113), it may be possible to get a short-term payment to help fund some of their care. If your relative or friend would like to consider this, they should discuss it with a solicitor.

We have more information about supporting someone with cancer:

- Visit **macmillan.org.uk/carers** to read the information online.
- Visit **be.macmillan.org.uk/carers** to order free information.
- Call us on **0808 808 00 00** to order the information you need.

Talking about cancer

As a relative or friend, you may find it hard to talk about cancer or share your feelings. You might think it is 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 are 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 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. Usually, it is enough just to listen and let the person with cancer talk when they are ready.

You may find our booklets **Talking with someone who has cancer** and **Looking after someone with cancer** helpful. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy.

Financial help

If you are a carer, you may be entitled to financial help, such as the Carer's Allowance. You can get more information about this benefit, and any others that you may be entitled to, by speaking to one of our Welfare Advisers on **0808 808 00 00**.

Inquest after someone dies

There may come a time when treatments are no longer working for your relative or friend and you have to prepare for their death. When someone dies of mesothelioma, there will need to be an inquest. This is a legal investigation into the circumstances surrounding a person's death. At such a difficult time, it can be even harder if you did not know this.

An inquest is needed because mesothelioma is an occupational disease. When a person with mesothelioma dies, the doctor who signs the death certificate must inform the coroner (the procurator fiscal in Scotland) who will carry out the inquest. A coroner is a doctor or lawyer who investigates unexpected deaths.

The need for an inquest will not usually mean any delay before your relative or friend's funeral can take place. The coroner will issue a temporary death certificate in most cases. This is because a full certificate cannot be issued until after the inquest is completed. This may take a few months.

The coroner will decide if a post mortem (an examination of the body) is needed to find out whether the death was due to mesothelioma or another cause. In many situations, a post mortem is not needed if there is enough medical evidence to confirm the person had mesothelioma. This evidence may come from samples (biopsies) that were taken when the person was first diagnosed with mesothelioma.

If your friend or relative was making (or had already made) a compensation claim, the coroner should be told and given the solicitors details. The solicitor should also be told of the death soon after the person passes away. In most cases, the solicitor will be able to advise and deal with the coroner on behalf of the family.

It can be distressing when you have to deal with these issues as well as the possible death of your relative or friend. You may wish to get support from your specialist nurse or a support organisation (see pages 129 to 133). You can also call us on **0808 808 00 00** if you need support.

Compensation for family members

Relatives of people who have died from mesothelioma may be able to claim compensation for their relative's pain and suffering, and some financial losses suffered as a result of the illness. This may not be possible if the person who died from mesothelioma had already made a claim which had been settled.

It is important to get legal advice from a specialist solicitor on how to make a claim.


HOUSING COSTS
HOUSING COSTS
HOUSING COSTS
CANCER AND OLDER PEOPLE

FURTHER INFORMATION

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.

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** 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
- eBooks
- 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.

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 to Friday, 9am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- 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 guidance

Our financial team can give you guidance 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**

My Organiser app

Our 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.

Mesothelioma support organisations

Asbestos Victims Support Group Forum UK
Tel 0161 636 7555
Email
asbestos.mcr@gmail.com
www.asbestosforum.org.uk
Organisation representing asbestos victims support groups. You can find your local support group by selecting 'Forum members' on the website.

Association of Personal Injury Lawyers (APIL)
Tel 0115 943 5400
Email mail@apil.org.uk
www.apil.org.uk
Helps find lawyers for people who are seeking compensation for injury or work-related illnesses.

British Lung Foundation
Helpline 03000 030 555
(Mon to Fri, 9am to 5pm)
www.blf.org.uk
Supports people affected by any type of lung disease. Runs Breathe Easy support groups across the country. The Mick Knighton Mesothelioma Research Fund (MKMRF) raises awareness and funds research into mesothelioma through the British Lung Foundation – find more information at **www.blf.org.uk/support-for-you/mesothelioma/mkmrf**

June Hancock Mesothelioma Research Fund
Tel 0114 274 4420
Email
info@junehancockfund.org
www.junehancockfund.org
Supports people with mesothelioma and their carers. Raises funds for research into mesothelioma.

Mesothelioma UK

Helpline 0800 169 2409
(Mon to Fri, 8.30am to 4.30pm)
Email
info@mesothelioma.uk.com
www.mesothelioma.uk.com
A national organisation providing up-to-date information for patients with mesothelioma and their carers through its helpline.

Veterans UK

Helpline 0808 1914 218
(Mon to Fri, 8am to 5pm)
Email veterans-uk@mod.uk
www.gov.uk/government/organisations/veterans-uk
Aims to improve personnel, pensions, welfare and support services to members of the armed forces and veterans.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support.

Cancer registries

National Cancer Registration Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncr.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel 013 1275 7777
Email nss.csd@nhs.net
www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Emotional and mental health support

Samaritans

Helpline 116 123
Email jo@samaritans.org
www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year.

Financial or legal advice and information

Citizens Advice

Find details for your local office by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

Civil Legal Advice

Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm,
Sat, 9am to 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.

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Helpline
0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)
Carer's Allowance Unit
Tel 0345 608 4321
Textphone 0345 604 5312
(Mon to Thurs, 8.30am to 5pm,
Fri, 8.30am to 4.30pm)
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm,
and Sat 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling.

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 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 Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales)
0808 808 7777
(Mon to Wed, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

Advanced cancer and end-of-life care

Marie Curie

Helpline 0800 090 2309
(Mon to Fri, 9am to 6pm,
Sat, 11am to 5pm)
www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Bereavement support

Cruse Bereavement Care

Helpline 0808 808 1677
(Mon and Fri, 9.30am to 5pm,
Tues to Thurs, 9.30am to 8pm)
Email helpline@cruse.org.uk
www.cruse.org.uk

Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website.

Disclaimer

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr David Gilligan, Consultant Clinical Oncologist. With thanks to: Mr Tom Cecil, Consultant Colorectal Surgeon; Lorraine Creech, Mesothelioma Clinical Nurse Specialist; Juliet King, Consultant Thoracic Surgeon; Roger Maddocks and colleagues at Irwin Mitchell Solicitors; Professor Allan Price, Consultant Oncologist; and Rachel Thomas, Lung Cancer and Mesothelioma Clinical Nurse Specialist. Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories. We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

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

Alexander, R and Burk, A. 2015. Diagnosis and Management of Patients with Malignant Peritoneal Mesothelioma. Journal of Gastrointestinal Oncology. Vol 7 (1) pp. 79 to 86.
ESMO Guidelines 2015. Malignant Pleural Mesothelioma: Clinical Practice Guidelines. Annals of Oncology. Vol 26 (5) pp. 31 to 39.
Royal College of Physicians. National Lung Cancer Audit Pleural Mesothelioma Report 2016 (for the audit period 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.

5 WAYS YOU CAN HELP SOMEONE WITH CANCER

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

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Mr/Mrs/Miss/Other

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Surname

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Postcode

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Email

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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

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Visa / MasterCard / CAF Charity Card / Switch / Maestro

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Security number

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I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand 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.

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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

27530

This booklet is about mesothelioma. It is for anyone who has been diagnosed with mesothelioma. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of pleural and peritoneal mesothelioma. It explains how they are diagnosed and how they may be treated. It also has information about emotional, practical and financial issues.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call our support line.

Health & care information you can trust
The Information Standard
Certified Member

What's this logo? Visit **macmillan.org.uk/ourinformation**

WE ARE MACMILLAN.
CANCER SUPPORT