

# Understanding mesothelioma





# About this booklet

**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 these types of mesothelioma are diagnosed and how they may be treated. It also has information about looking after yourself and getting support. 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

This booklet is split into sections to help you find what you need. You do not 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.

On pages 132 to 140, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (page 141).

## Quotes

In this booklet, we have included quotes from people who have had mesothelioma, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.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**, 7 days a week, 8am to 8pm, or visit [macmillan.org.uk](https://www.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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK 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](https://www.macmillan.org.uk/otherformats) or call **0808 808 00 00**.

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# MESOTHELIOMA

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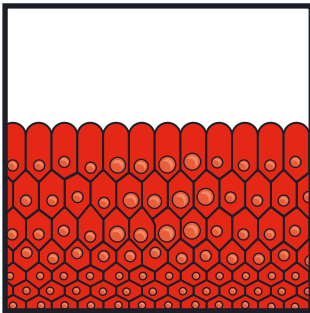
# What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

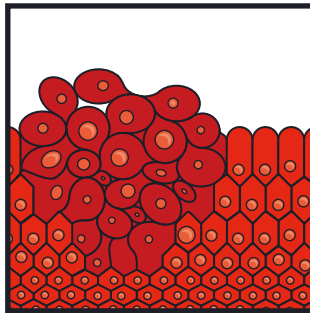
Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

## Cells forming a tumour

Normal cells



Cells forming a tumour





Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

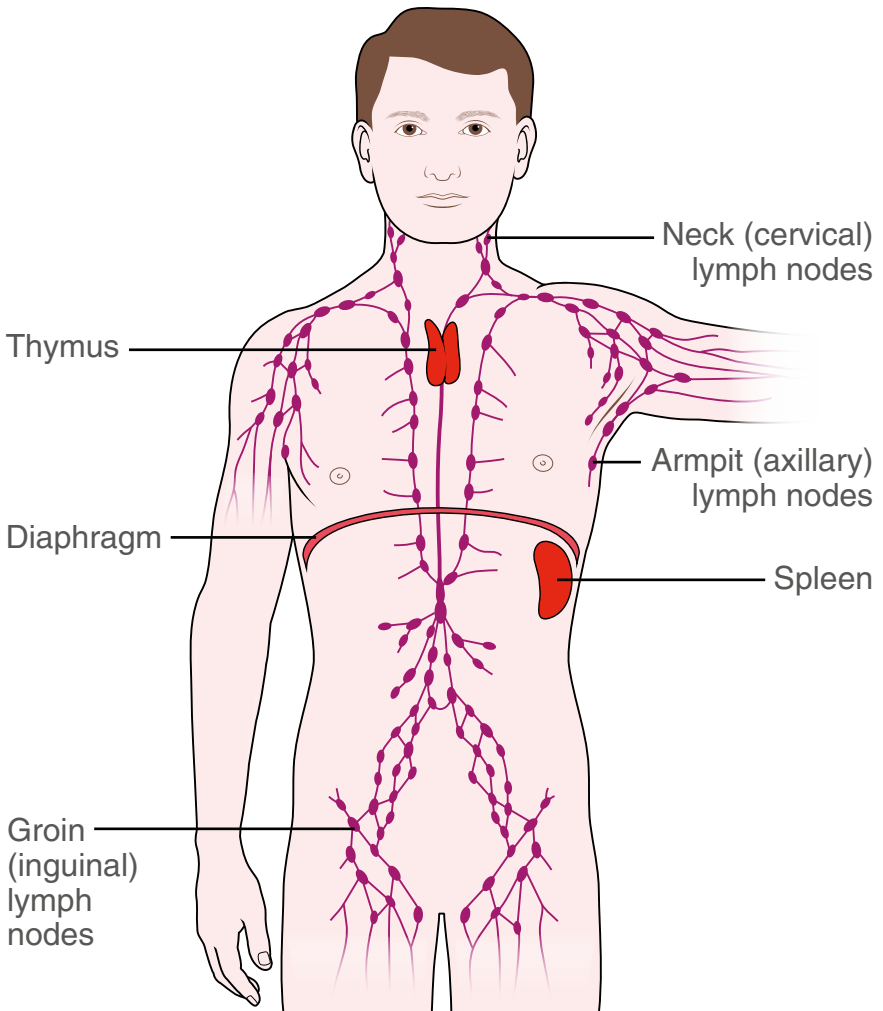
Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (pages 8 to 9). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

# The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

# 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 organs in the body. It also lines the spaces (cavities) within the body, such as the chest and abdominal cavity.

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 tummy (abdomen) is called the peritoneum.

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

## Pleural mesothelioma

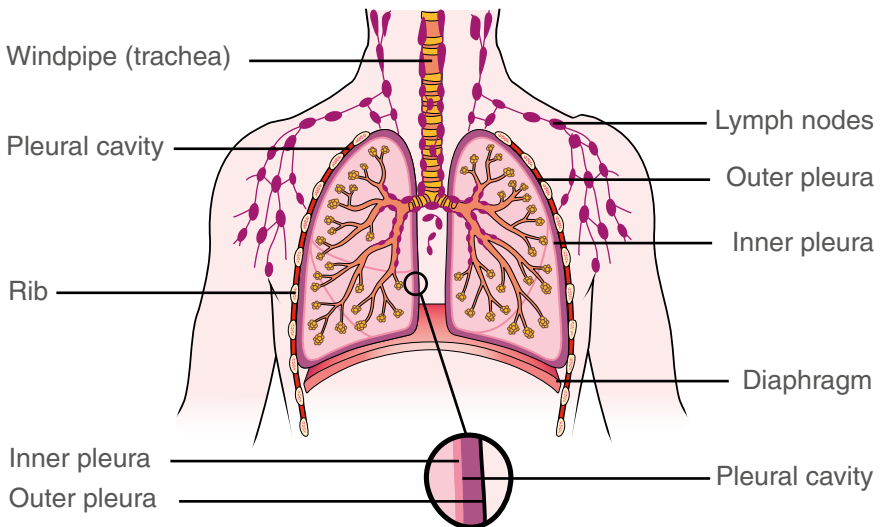
The lungs sit within the chest, on either side of the heart. They take in air and supply oxygen to the organs and tissues of the body.

The lungs are covered by a lining (membrane) called the pleura, which has 2 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.

Between the 2 layers, in a space called the pleural cavity, is a small amount of fluid. This fluid acts as a lubricant. It 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 2 layers of the pleura. This is called a pleural effusion.

## Structure of the lungs and pleura

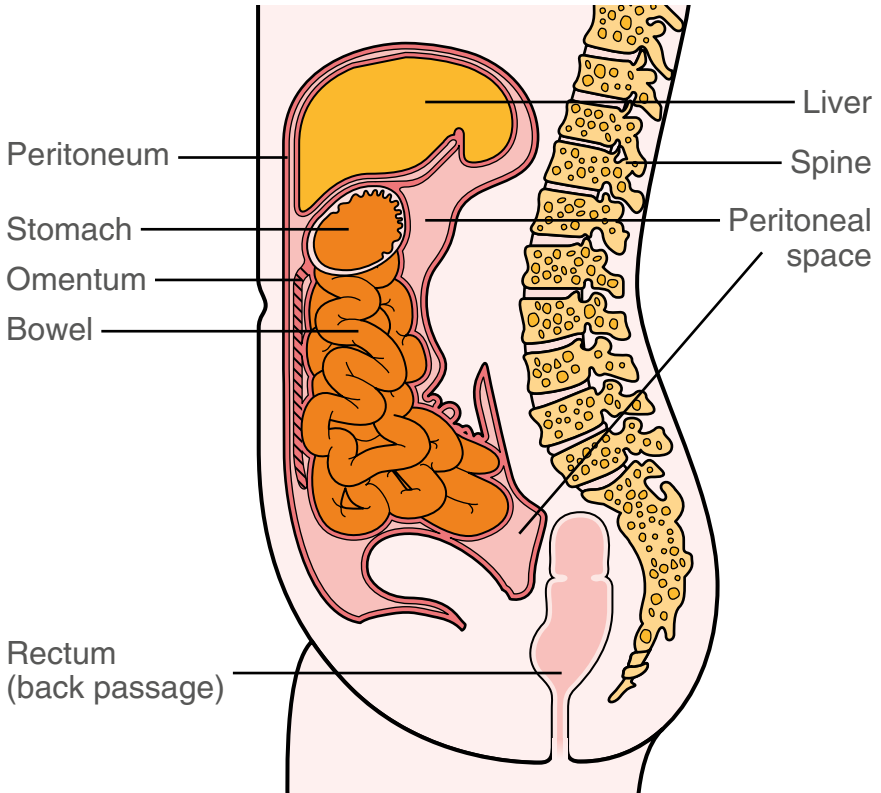


## Peritoneal mesothelioma

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. When mesothelioma develops in the peritoneum, it causes the layers of the peritoneum to thicken. Fluid may also collect between the 2 layers. This is called ascites.

# Side view of the tummy (abdomen) showing the peritoneum



## Cell types of mesothelioma

Pleural and peritoneal mesothelioma can be grouped by how the cells look under a microscope. There are 3 main types:

- epithelioid – this is the most common type
- sarcomatoid
- mixed or biphasic – this has both epithelioid and sarcomatoid cells
- cystic and papillary – these are rare and slow growing types of peritoneal mesothelioma.

Knowing the type of cell involved may give your doctors more information about:

- the best treatment for you
- how the mesothelioma may 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

Risk factors are what increase your chance of developing certain types of cancer. The most common cause of mesothelioma is exposure to asbestos.

## Asbestos

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 3 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, brown and white asbestos is linked with mesothelioma.

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

## **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 tries to break them down and remove them. This causes inflammation in the lung tissue, which can cause lung disease.

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.

## **Peritoneal mesothelioma**

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

## Exposure to asbestos

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

- joiners and construction workers
- plumbers
- electricians
- boilermakers
- launderers
- dock workers and shipbuilders.
- power station workers
- people who served on warships.

Mesothelioma is 5 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. This is called environmental exposure. For example, this might include:

- 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 (pages 106 to 114).

Sometimes, mesothelioma develops in people who did not know, or perhaps cannot remember, 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
- changes in certain genes – this may cause a higher risk of developing mesothelioma, but you would still have to be exposed to asbestos for it to develop.

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

Doctors do not know why some people who are exposed to asbestos get mesothelioma and others do not.

**My cancer, mesothelioma, is not caused through smoking, it is caused through working with asbestos when I was a young man.**

John

# 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) and heavy sweating at night
- extreme tiredness (fatigue)
- weight loss
- loss of appetite
- a cough that does not go away.

## 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 in your normal bowel function, 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.

I suppose I should have been angry, but I wasn't. I think I've accepted that it was just a risk of working in the late 1960s and early 1970s. I didn't know. I knew that I was being exposed to asbestos, I didn't know the dangers. Obviously since then, I've learnt about the dangers of asbestos.

Peter

# DIAGNOSING MESOTHELIOMA

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# How mesothelioma is diagnosed

You usually begin by meeting your GP. They will ask you about your symptoms and examine you. They may also ask if you have been exposed to asbestos in the past. You may have blood tests and a chest x-ray (page 26).

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

The specialist may ask if you have been exposed to asbestos in the past. This might include jobs you have had or places you have worked. 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. You may have to think back to your childhood or early working years.

**When you first get the news that you have got cancer it is just numbing, you really don't know how you're going to cope.**

Peter

# Tests for pleural mesothelioma

Pleural mesothelioma (pages 10 to 11) 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 2 layers of the pleura (pleural effusion), this usually shows up on a chest x-ray at an earlier stage. A pleural effusion (page 11) can also develop because of other cancers and some non-cancerous conditions. You may need to have a few different tests before your doctors can make a diagnosis. Your doctor or nurse will tell you about the most suitable tests for you and what they involve.

## Draining fluid from the pleura (pleural aspiration)

Mesothelioma cells can cause fluid to build up between the 2 layers of the pleura around the lung. This is called a pleural effusion (page 11). Draining the fluid may help with your breathing. Your specialist doctor may take a sample of this fluid to be checked for mesothelioma cells.

## Pleural biopsy

During a biopsy, a small piece of tissue is removed so that it can be looked at under a microscope. Your doctor may suggest a biopsy of the thickened pleura.

A pleural biopsy is more likely to confirm the diagnosis of mesothelioma than a sample of fluid. Your doctor may take a pleural biopsy in different ways.

## 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 makes a three-dimensional (3D) picture of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast 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. This is because you could have a more serious reaction.

The scan takes 5 to 10 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner.

We have a video on our website that has more information about having a CT scan – visit [macmillan.org.uk/ct-scan](http://macmillan.org.uk/ct-scan)

## **CT or ultrasound guided biopsy**

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

## **Thoracoscopy**

The doctor uses a thin tube (thoracoscope) to look at the pleura and the area around the lungs. They may also take biopsies.

You will have either a general anaesthetic, or a local anaesthetic with a sedative to make you sleepy. The specialist doctor makes a small cut in your chest wall. They then put the thoracoscope into your chest. The tube has a light and camera at the end, so the doctor can see into your chest. The doctor then drains off any fluid and takes a biopsy.

Sometimes the doctor uses a video camera with the thoracoscope when taking biopsies. This is called video-assisted thoracoscopic surgery (VATS). It can help the doctor see the area around the lung more clearly and, if needed, do complex operations.

## Talc pleurodesis

After draining fluid or taking a biopsy, the doctor may put a sterile, medical grade talcum powder (talc) between the layers of the pleura. This helps prevent the fluid coming back. This is called talc pleurodesis. They put the talc through the tube in your chest and into the pleural space. This helps stick the 2 linings together, to help stop the fluid from building up again.

A small, rubber tube may be left in place in your chest to drain any fluid and help your lung expand. This tube is removed after a few days.

If your lung does not expand, the doctors might leave a small tube inside the space between the pleura. It is about the size of a straw and is called an indwelling pleural catheter (IPC). This can be used at home to drain the fluid and prevent breathlessness.

## After the biopsy

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

After the doctor has taken the biopsy, they will send it to the laboratory. A doctor who looks at cells or body tissue under a microscope to diagnose cancer (pathologist) will look at the biopsy.

Sometimes, even after taking a biopsy the doctors may not be sure of the diagnosis. This is because it can be difficult to find the difference between pleural mesothelioma and 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 done again, or you may be referred to another hospital for a second opinion.



# Tests on the lymph nodes around the lungs

You may have tests on the lymph nodes (pages 8 to 9) around the lungs. This is not common, but may happen if:

- your doctor thinks you might be able to have surgery to treat the mesothelioma
- you were having tests for lung cancer before mesothelioma was diagnosed.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to 2 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 a support organisation (pages 132 to 140) can also provide support. You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).



# Tests for peritoneal mesothelioma

You may have several different tests to help diagnose peritoneal mesothelioma.

## Abdominal x-ray

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

## CT (computerised tomography) scan

A CT scan makes a three-dimensional (3D) picture of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast 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. This is because you could have a more serious reaction.

The scan takes 5 to 10 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner.

We have a video on our website that has more information about having a CT scan – visit [macmillan.org.uk/ct-scan](http://macmillan.org.uk/ct-scan)

## MRI (magnetic resonance imaging) scan

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner. They may give you an injection of a dye, called a contrast. It helps show certain areas of the body more clearly.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes 15 to 90 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

## Draining fluid from the abdomen (peritoneal aspiration)

Mesothelioma cells can cause fluid to collect in the abdomen. This is called ascites (pages 84 to 85). 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. Your doctor may suggest a biopsy of the peritoneum (lining that covers the organs in the tummy) to help diagnose peritoneal mesothelioma (pages 12 to 13). It can be done in 2 ways.

## Laparoscopy

This allows the doctor to look at other areas in your tummy (abdomen) and take more biopsies if needed. It 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. They will also check nearby organs to see if the mesothelioma has spread.

## CT or ultrasound guided biopsy

The doctor will give you a local anaesthetic to numb the area. They use an ultrasound or a CT scan (pages 31 to 32) to help guide them to the right place. Then, they 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 small 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, tell your doctor or nurse.

After the doctor has taken the biopsy, they will send it to the laboratory. A doctor who looks at cells or body tissue under a microscope to diagnose cancer (pathologist) will look at the biopsy.

Sometimes, even after taking a biopsy, the doctors may not be sure of the diagnosis. This is because it can be difficult to find the difference between peritoneal mesothelioma and 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 done again, or you may be referred to another hospital for a second opinion.

# Staging of mesothelioma

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

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

- **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.

## Pleural mesothelioma

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

This is a simplified version of the IMIG system.

### Stage 1

Cancer cells are only 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 the following:

- **Stage 1a** – cancer cells are only 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 or the diaphragm.

### Stage 2

The cancer is in the same areas as stage 1 but has also spread to nearby lymph nodes (N1).

## Stage 3

Stage 3 is divided into the following:

- **Stage 3a** – cancer cells have spread deeper into the tissues beneath the pleura. For example, they have spread:
  - 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).
- **Stage 3b** – cancer cells have spread further into the chest wall, through the pericardium or to nearby organs. It may or may not have spread to lymph nodes in the centre of the chest, or lymph nodes further away from the lungs (N2).

## Stage 4

The cancer has spread outside of the chest to another area of the body (metastasis or M1).

## Peritoneal mesothelioma

There is no specific staging system for peritoneal mesothelioma. But doctors sometimes 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).
- whether the cancer has spread outside the peritoneum or to any lymph nodes.

PCI is only used at specialist centres. 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, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. 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. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.



# TREATING MESOTHELIOMA

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# Treatment overview

Treatment for mesothelioma can include chemotherapy, radiotherapy and sometimes surgery (pages 49 to 70).

Doctors are also researching whether other types of treatments called targeted therapies and immunotherapies may be helpful to treat mesothelioma.

## How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

## Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- Chest physician – a doctor experienced in lung disease (if you have pleural mesothelioma).
- Clinical oncologist – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.

- Surgeon – a doctor who does operations (surgery). They will be experienced in chest surgery, if you have pleural mesothelioma (pages 64 to 65) or abdominal surgery, if you have peritoneal mesothelioma (page 69).
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Palliative care nurse – a nurse who helps with symptom control and end-of-life care.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

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

- a physiotherapist – someone who gives advice about exercise and mobility
- a counsellor – someone who is trained to listen to people's problems and help them find ways to cope
- a psychologist – someone who gives advice about managing feelings and behaviours
- a social worker – someone who can help sort out practical and financial problems
- a dietitian – someone who gives information and advice about food and food supplements.

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.

Sometimes 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. This can help you remember the discussion. You may find it useful to make a list of questions before the appointment and to take notes.



## 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 and peritoneal mesothelioma, the cancer has already spread when it is diagnosed and treatment is given with the aim of slowing the growth of the cancer. This can lead to an improvement in symptoms and a better quality of life. However, for some people, the treatment will have no effect on the cancer and they will get the side effects of the treatment with little benefit.

If the cancer is advanced and has spread to other parts of the body, treatment may only be able to control it, improving symptoms and quality of life. However, for some people in this situation the treatment will have no effect on the cancer and they will get the side effects without any of the benefit.

If you have been offered treatment that aims to cure the cancer, deciding whether to accept it may not be difficult. But, if a cure is not possible and the purpose of treatment is to control the cancer for a period of time, it may be more difficult to decide whether to go ahead.

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

## Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (pages 42 to 44).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.



## Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you meet for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion in our booklet **Making treatment decisions** (page 128).



# Treatment for pleural mesothelioma

It is rarely possible to cure mesothelioma. Treatment is given to help control symptoms and to slow the growth of pleural mesothelioma.

Treatments may include chemotherapy (pages 50 to 56), radiotherapy (pages 58 to 62) and immunotherapy (page 66). You may also have other treatments to help control symptoms (pages 80 to 91). These are called supportive therapies.

Sometimes, surgery may be an option if:

- mesothelioma is diagnosed before it has spread
- it has only spread to nearby tissues.

We have more information in our booklet **Side effects of cancer treatment** (page 128).

## 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.

Chemotherapy will not cure pleural mesothelioma, but it can help to slow the cancer's growth and may help some people to live longer. It may also help with symptoms such as pain and breathlessness. Your doctor will tell you if chemotherapy is suitable for you.

### How chemotherapy is given

Chemotherapy drugs for pleural mesothelioma are usually given by injection into a vein (intravenously), or by a drip (infusion). 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 (pages 35 to 37) and how well it is responding to treatment.

## Chemotherapy drugs

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 also be given vitamin B12, folic acid and steroids. These help to reduce the side effects of treatment.

Other chemotherapy drugs are sometimes used. These may be given as part of a clinical trial (pages 72 to 74).

We have more information about clinical trials on our website – visit [macmillan.org.uk](http://macmillan.org.uk)

We have more information about chemotherapy and the drugs mentioned on our website – visit [macmillan.org.uk/treatments-and-drugs](http://macmillan.org.uk/treatments-and-drugs)

## 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

This treatment 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 sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you 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 treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

## Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

## Anaemia (low red cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

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

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. 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 often and eat small amounts regularly. It is important to drink enough fluids.

If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

## Sore mouth and throat

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

If your mouth or throat 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 and throat.

Sucking ice chips may sometimes help relieve mouth or throat pain. But if you are having radiotherapy to the head or neck, do not suck on ice. It can cause damage.



## Diarrhoea

This treatment may cause diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

If you have diarrhoea:

- try to drink at least 2 litres (3½ pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

## 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. 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.

We have more information about in our booklet **Coping with tiredness (fatigue)** – page 128. If you finding reading tiring, you can listen to the audiobook at [macmillan.org.uk/fatigueaudio](http://macmillan.org.uk/fatigueaudio)

## 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 finishes. Your nurse can talk to you about ways to cope with hair loss.

We have more information about chemotherapy drugs and side effects on our website (page 128).



## 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
- sometimes alongside surgery (pages 64 to 65) and chemotherapy (pages 50 to 56), as part of a clinical trial (pages 72 to 74).

You may only need 1 or 2 treatments. Or you may need a course of treatment over a few days or weeks.

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

## Planning your radiotherapy

Before you start your treatment, radiotherapy must be carefully planned. This helps to make sure it is as effective as possible, while 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 (pages 31 to 32), 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 have to lie still for a few minutes during the treatment.

At the beginning of each treatment session, the radiographer positions you carefully on the couch and makes sure you are comfortable. When you are in the correct position, the radiographers leave the room and you are given your treatment. The radiographers can 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 tell you 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.

Side effects should slowly improve after your course of treatment ends. But it is important to tell your doctor know if they continue.

## Tiredness

Radiotherapy often makes people feel tired. Tiredness may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired. But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as short walks
- eat a healthy diet and drink plenty of fluids
- ask others for help with everyday jobs.

After treatment finishes, you may continue to feel tired for weeks or months. If it does not get better, tell your cancer doctor or specialist nurse.

We have more information in our booklet about **Coping with tiredness (fatigue)** – page 128.

## 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 1 to 2 weeks of treatment, you may have difficulty 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 oesophagus).

Tell your doctors if you have problems swallowing. They can give you medicines to help. If you do not feel like eating, or have problems swallowing, talk to your doctor or a dietitian. They may recommend you have some high-calorie drinks to help. You can get these from your GP or from most chemists. We have more information in our booklet **Eating problems and cancer** (page 128).

## Cough

You may develop a cough during or after radiotherapy. This usually improves 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

Your treatment may make you feel sick (nausea) and be sick (vomit). Tell your doctor if this happens. They can give you anti-sickness drugs (anti-emetics) to help.





## Surgery for pleural mesothelioma

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

Surgery to try to remove mesothelioma or help people live longer is called radical surgery. Radical surgery is only possible in a very small number of people with mesothelioma. 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 surgeons (thoracic surgeons) who are experienced in treating mesothelioma. Sometimes, surgery may be done as part of a clinical trial (pages 72 to 74).

## 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 layers removed. This operation is called a pleurectomy decortication, or PD.

Sometimes, surgeons do a smaller operation to remove only some of the pleura (partial pleurectomy). This can help with symptoms, for example it can help reduce the build-up of fluid in the pleura (pleural effusion), or to re-expand the lung.

It may be possible to have the partial pleurectomy using 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 that goes from your side below your armpit round to your back below your shoulder blade (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 tummy (diaphragm). This is called an extended pleurectomy decortication (EPD). The surgeon will then reconstruct the pericardium and diaphragm. This is major surgery and you must be well enough to have it.

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

## Immunotherapy for pleural mesothelioma

The immune system protects the body against illness and infection. Immunotherapies are treatments that use the immune system to find and attack cancer cells. Some people with pleural mesothelioma may be offered immunotherapy, if they have not any previous treatment. The drugs used are nivolumab and ipilimumab. They are usually given in combination. These drugs are also called checkpoint inhibitors.

Immunotherapies for mesothelioma are likely to become more widely available soon.

Nivolumab may also be offered to some people who have already had chemotherapy (pages 50 to 56) and need further treatment. Your doctor can talk to you about what is right for your situation.

# Treatment for peritoneal mesothelioma

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

Treatments may include chemotherapy, and other treatments that are sometimes called supportive therapies.

Very rarely surgery (page 69), 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 tell you if chemotherapy is suitable for you.

## How chemotherapy is given

Chemotherapy drugs for peritoneal mesothelioma are usually given as a drip (infusion) or 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 (pages 35 to 37) and how well it is responding to treatment.

## Chemotherapy drugs

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 treatment.

Other chemotherapy drugs are sometimes used. These may be given as part of a clinical trial (pages 72 to 74).

We have more information about chemotherapy and the drugs mentioned on our website. Visit [macmillan.org.uk/treatments-and-drugs](https://www.macmillan.org.uk/treatments-and-drugs)

The most common side effects of pemetrexed and cisplatin are described on pages 51 to 56.

## Surgery for peritoneal mesothelioma

Surgery is only suitable for a small number of people with peritoneal mesothelioma. It depends on the stage of the mesothelioma 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 gallbladder, and sometimes part of the bowel. You may also need to have the womb and ovaries removed. People who have a womb and ovaries include women, transgender (trans) men and people assigned female at birth.

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

When the surgeon has removed all or most of the tumours, they may put a heated chemotherapy drug into your tummy. This is called hyperthermic intraperitoneal chemotherapy (HIPEC) – page 70.

The operation will be done by a 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.

## Chemotherapy into the abdomen

If you are having surgery for peritoneal mesothelioma, 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.

During the operation, the surgeon removes all, or most, of the tumours that they can see. They then wash out the area to remove any loose mesothelioma cells, and put chemotherapy into the tummy (abdomen). The chemotherapy drugs used are usually doxorubicin and cisplatin.

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 a vein. Your doctor or nurse will explain what to expect.





# Clinical trials

Clinical trials are medical research studies involving people.

Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

## Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about taking part in a trial on our website – visit [macmillan.org.uk/clinical-trials](https://www.macmillan.org.uk/clinical-trials)

## Giving blood tissues and samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

# 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 speak to a physiotherapist if you need help with your mobility or advice on breathing exercises (page 76).

## 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 (page 139).

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



# CONTROLLING SYMPTOMS OF MESOTHELIOMA

Controlling symptoms

80





# Controlling symptoms

For people with mesothelioma, the main aim of treatment is to control symptoms. The symptoms of pleural and peritoneal mesothelioma can be controlled in many ways.

Your cancer doctor, specialist nurse or GP can help you manage your symptoms. They may refer you to a palliative care team. These teams specialise in managing symptoms and giving emotional support to you and your family. Palliative care teams have specialist nurses who can sometimes visit you at home.

## Treatments to control symptoms of pleural mesothelioma

There are different treatments that can help to control the 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 2 layers of the pleura (the membranes that cover the lungs). This is called a pleural effusion.

### 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 onto 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. We have more information in our booklet **Managing breathlessness** (page 128).



## 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.

## Indwelling pleural catheter (IPC)

Breathlessness or a cough may cause a build-up of fluid (pleural effusion). To help drain the fluid, you can have a small tube inserted into your chest. This is called an indwelling pleural catheter (IPC), and it is put in under local anaesthetic. The tube is about the size of a straw and can open and close at the end.

You can drain the fluid whenever it starts to build up. This might be once a day or every few days, depending on how quickly it builds up. The tube connects to a bottle which you can then disconnect and empty. The rest of the time the tube is not noticeable, it will be under your clothes and does not affect daily activities.



## Treatments to control symptoms of peritoneal mesothelioma

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

### Ascites

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

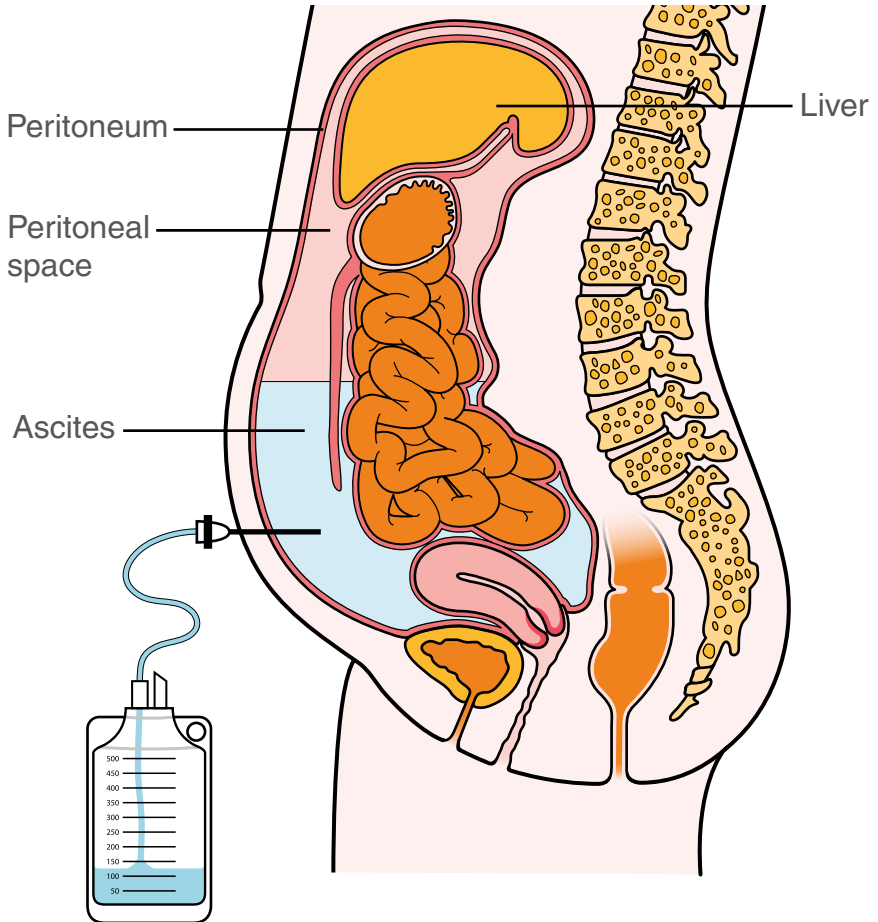
Doctors can treat ascites by putting in a small tube to drain off the fluid from your tummy. This helps to relieve the symptoms. They will give you a local anaesthetic in your tummy to numb the area first. The doctor then makes a small cut in the skin and gently inserts the tube. They attach the tube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

The tube is usually taken out after the fluid is drained. But sometimes it stays in for a few days. It depends on the amount of fluid that needs to be drained.

If the fluid builds up again, you may need it drained off more than once. If it continues to build 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 pass urine (pee) more often. It may help stop the fluid building up in the tummy.

## Side view of the abdomen showing drainage of ascites



## Managing a blocked bowel (bowel obstruction)

Sometimes, peritoneal mesothelioma causes the bowel to become blocked. Symptoms of a blocked bowel may include:

- pain
- feeling bloated
- 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. Tell your doctors or specialist nurse if you have pain so that they can treat it early on.

### Painkillers

There are many 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 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 a record 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:

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

Sometimes, 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. Tell your doctor 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 having drinks that contain caffeine before you go to bed, or during 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 you do not have much of an appetite, 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 may prescribe them for 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. We have more information in our booklet **Eating problems and cancer** (page 128).

## Tiredness

Many people with mesothelioma feel tired and have less energy to do the things they normally do. This may be because of the illness, or it may be a side effect of treatment. It is important not to do too much. Try to balance rest with gentle exercise, such as walking. Some people find it helpful to set goals to plan their daily activities. These goals may include:

- cooking a simple 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 whether you have anaemia. You may need a blood transfusion if you are very anaemic.

Some people may be tired because they have difficulty sleeping. This may be caused by some treatments, or by the emotional effects of cancer. We have more information on how to improve things if you are having difficulty sleeping.

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 with depression.

We have more information in our booklets **Coping with fatigue (tiredness)** and **How are you feeling? The emotional effects of cancer** (page 128).

## 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 doctor or GP first. This is important because you will need to avoid some complementary therapies during, and for a short time after, cancer treatments. We have more information in our booklet **Cancer and complementary therapies** (page 128).





# **YOUR FEELINGS AND RELATIONSHIPS**

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# Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

## Shock and denial

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

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

## Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

## Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

## Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

## Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Our website can help you find local support groups. Visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people affected by cancer on our Online Community. Visit **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**.

# If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

We have more information in our booklet **Talking with someone who has cancer** (page 128).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone who has cancer** (page 128).

# Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

## Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 128).

# Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse. We have more information in our booklet **How are you feeling? The emotional effects of cancer booklet** (page 128).

# FINANCIAL HELP AND WORK

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# Financial help and benefits

Most people who have been diagnosed with mesothelioma can get financial help. There are 2 main ways of getting financial help:

- benefits paid by the Department for Work and Pensions (DWP)
- compensation from you or your spouse's employer – this may be your current employer or a former one who was linked to your exposure to asbestos.

If you have been diagnosed with mesothelioma, you should find out more about getting both these types of financial help.

## Benefits

People often think that benefits paid by the government are means-tested, and that whether you can get them depends on your savings and income. It is important to remember that although some benefits are means-tested, many are not.

A benefits adviser or your solicitor will be able to tell you more about which benefits you can claim.

You can also get more information from our money advisers by calling the Macmillan 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 or Mesothelioma UK (pages 132 to 133).

## 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 if you can get a benefit called Employment and Support Allowance (ESA).

ESA provides support to people under State Pension age who can do some work (permitted work). There are different types of ESA, so it is a good idea to speak to a money adviser to find out if you can make a claim. Call **0808 808 00 00** to speak to a Macmillan money adviser.

## Personal Independence Payment and Attendance Allowance

These benefits are for people who have difficulty moving around or looking after themselves. Personal Independence Payment (PIP) is for people aged 16 to State Pension age. PIP has replaced the Disability Living Allowance (DLA) for adults.

Attendance Allowance (AA) is a benefit for people who are at or above State Pension age.

There are special rules for people who are terminally ill and applying for PIP or AA. If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 12 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 12 months.

## Industrial Injuries Disablement Benefit

You can claim Industrial Injuries Disablement Benefit if you were employed in a job, or on an employment training scheme or course, that caused you to have a disease or an accident. It is an important benefit for people with certain asbestos-related illnesses, including mesothelioma.

It is payable if the mesothelioma may have been caused by exposure to asbestos dust at work. This includes people who have worked abroad for a UK company. You do not need to have worked with asbestos to get this benefit. You only need to have been exposed to asbestos dust at work. You cannot get this benefit if you were self-employed. You may still be able to get this benefit if you are retired.

You should always get advice from a solicitor about making a claim for Industrial Injuries Disablement Benefit (IIDB). You will need to give information about where you were exposed to asbestos as well as how you were exposed. It is very important that the information on the benefit application form is filled in correctly. It may affect your claim for this benefit or other compensation claims if the form is not filled in correctly.

IIDB can be paid into your bank account every week, 4 weeks or 13 weeks.

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 welfare rights adviser or specialist solicitor.

## Lump sum payments

You may be able to get a one-off, lump-sum payment if you were exposed to asbestos dust at work and have mesothelioma. If you have mesothelioma that was not caused through employment, you may still be able to get a payment. You may also be able to get a payment if you were exposed to asbestos while working abroad for a UK company.

You can apply for the lump sum through different schemes. But the payments are the same and the application is made on the same form. The DWP will work out which scheme the payment will be made from. The 2 schemes are:

- The Pneumoconiosis etc. (Workers' Compensation) Act 1979 (PWCA).
- Diffuse Mesothelioma Payments 2008 scheme (DMPS).

You should always get advice from a solicitor about making a claim for a lump sum payment. You will need to give information about where you were exposed to asbestos, as well as how you were exposed. It is very important that the information on the benefit application form is filled in correctly. Incorrect information may affect your claim for this benefit, or other compensation claims.

There are time limits for making a claim under either scheme. These are:

- under the PWCA scheme, 1 year from the award of IIDB
- under the DMPS, 1 year from diagnosis.

You should speak to a specialist solicitor straight away who can advise you about your claim.

## Diffuse Mesothelioma Payment Scheme (DMPS)

This scheme provides payments for people who were diagnosed with mesothelioma on or after 25<sup>th</sup> July 2012.

The scheme is only used when someone with mesothelioma has not been able to claim compensation anywhere else.

It is only for people who were exposed to asbestos at work, and have both of the following:

They have a legal claim against their employer which has merit.

They have been unable to find the employer (because they have stopped trading), or the employer's insurer. Or, the employer is unable to meet the claim because they have no assets.

These must be the only reasons why they cannot successfully make a claim.

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 (PWCA). If you already have a payment from one of these schemes, the amount will be taken away 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. To get compensation from a former employer (or their insurer), the claim must be fully investigated first. If this has not been done, the claim will be rejected. The information given to support 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](https://www.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. The claim would be made with your local Veterans Advisory and Pensions Committee. Call the Veterans UK helpline on **0808 1914 218** for more information.

You may also be able to make a civil compensation claim with the help of a specialist solicitor. This may be if your exposure to asbestos dust in the armed forces happened:

- after 15<sup>th</sup> May 1987
- before 15<sup>th</sup> May 1987, because of the fault of non-services organisations such as private contractors or their employees.

## 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. If you were not exposed to asbestos at work, you may also be able to claim. For example, you could claim if you are a spouse who was exposed from handling contaminated work clothes.

This type of compensation claim requires specialist legal knowledge and must be made through an experienced, specialist solicitor. When choosing a solicitor, it is important to make sure that they have experience dealing with both asbestos-related disease claims and mesothelioma claims.

It is important to know that advertisements and websites offering legal advice may be misleading. Before choosing a solicitor, you may want to ask them some questions. Do not be afraid to ask them to explain anything that you have not understood, or to ask for more information.



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 (page 132).
- 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 (page 133).

For a compensation claim to be successful, you have to show that 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.

For example, this might be if you were exposed to asbestos when your employer knew, or should have known, about 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 (pages 108 to 109).

## Time limits for claiming compensation

Court proceedings for a claim 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 your exposure to the asbestos.

Family members of people who died from mesothelioma within 3 years of being diagnosed may still be able to make a claim. The 3-year period to make the claim begins from the date of death.

Sometimes this time limit can be extended. You can ask for advice from a specialist solicitor even if you think it may be too late to make a claim.

**My solicitor said, ‘You have to decide whether you want to get the benefit of compensation while you are alive or whether your widow claims when you are dead’. I thought, it will help us have a better life for my remaining years.**

**Anthony**

## Costs of claiming compensation

### England and Wales

Making a personal injury compensation claim in England and Wales should not cost you any money. Any specialist solicitor 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 the options for funding with the solicitor, before any claim is started.

Tell your solicitor if you:

- are a member of a trade union or a professional association
- have legal expenses insurance cover.

Your solicitor may take your case on a 'no win, no fee' basis. They will arrange insurance to protect you against the risk of having to pay the defendant's legal costs. The defendant is usually your former employer. 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 (the defendant). Most specialist solicitors offer arrangements where the insurance covers the cost of the premiums if the claim is unsuccessful. This means in that situation, there is no charge for the premium.

### Scotland and Northern Ireland

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.

## Compensation for family members

Family members of people who have died from mesothelioma may be able to claim compensation for:

- their relative's pain and suffering
- 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 about how to make a claim.

One of the specialist nurses came and talked to me and said, 'You really must think about claiming compensation'. She gave me some ideas of how to go about it and I contacted a solicitor recommended to me and who deals with industrial diseases.

Anthony

# Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (page 128). There is also lots more information at [macmillan.org.uk/work](http://macmillan.org.uk/work)

## Employment rights

If you have, or have ever had, cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (page 128).





# INFORMATION FOR CARERS

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# Looking after yourself

If you are a family member 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.

You may be very happy to do this, but there may be times when you need some extra support.

There are many health and social care professionals who can provide support for you and the person you are caring for. Tell your GP or nurse 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. Speak to your GP or nurse about this, so they can make sure you both get the support you need.

Getting support can also help your relationship with the person with cancer. Your relationship may have changed since you started looking after them. Having some help with caring may allow you to spend more time being a family member, partner or friend to your loved one.

It is important to look after yourself, as well as the person you are caring for. Try and make sure you eat well and keep active. When you get time off from caring, try to relax. Doing something you enjoy can help give you more energy and improve your mood. You could also spend time just sitting with and talking to the person you are caring for. This can be very rewarding. Try not to feel guilty – looking after yourself will help you care for you loved one better.

# Talking about cancer

As a family member or friend, you may find it hard to talk about cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared. But, not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often 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 (page 128).

## Financial help

If you are a carer, you may be able to get financial help, such as 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 money advisers on **0808 808 00 00**. We also have more information in our booklet **Help with the cost of cancer** (page 128).

If your family member or friend is making a compensation claim, it may be possible to get a short-term payment to help pay for some of their care. If they would like to consider this, they should discuss it with a solicitor.



# Coroner's inquest

There may come a time when treatments are no longer working for your family member or friend, and you have to prepare for their death. When a person with mesothelioma dies, the doctor must inform the coroner (the procurator fiscal in Scotland). The coroner will carry out an inquest. This is a legal investigation into the circumstances surrounding a person's death.

An inquest is needed because, in the UK, mesothelioma is almost always caused by exposure to asbestos dust. Death due to mesothelioma is not considered a natural death.

A coroner is a doctor or lawyer who investigates unexpected or unnatural deaths. An inquest does not usually cause any delay before your loved one's funeral can happen. 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. A post-mortem tries to find out if 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 family member or friend 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 about the death soon after the person dies. In most cases, the solicitor can advise and deal with the coroner on behalf of the family.

If a solicitor has been instructed to make a compensation claim, you should speak to them before making any decisions about:

- the inquest
- a post-mortem
- tissue samples.

Any decisions about these things may affect the claim, always speak to the solicitor first.

Dealing with these issues as well as the death of your loved one can be upsetting. You may want to get support from your GP, specialist nurse, or a support organisation. You can call our support line free on **0808 808 00 00**.







# FURTHER INFORMATION

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# About our information

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

## Order what you need

You may want to order more booklets or leaflets like this one.  
Visit [orders.macmillan.org.uk](https://orders.macmillan.org.uk) or call us on **0808 808 00 00**.

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

## Online information

All our information is also available online at [macmillan.org.uk/information-and-support](https://macmillan.org.uk/information-and-support) You can also find videos featuring 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
- interactive PDFs
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://macmillan.org.uk/otherformats)

If you would like us to produce information in a different format for you, email us at [informationproductionteam@macmillan.org.uk](mailto:informationproductionteam@macmillan.org.uk) or call us on **0808 808 00 00**.

# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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 support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our nurses about things like diagnosis and treatments from our nurse specialists
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit **macmillan.org.uk/support-line** to chat online and see the options and opening times.

### Macmillan Information and Support 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 would 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 is 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](https://www.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](https://www.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.

## Help with money worries

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

### Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

### Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit **macmillan.org.uk/financialsupport** for more information about benefits.

### Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line.

## Help with work and cancer

Whether you are 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**

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

## Mesothelioma support organisations

### Asbestos Victims Support Group Forum UK

Tel 01246 380 415

Email [info@asbestosforum.org.uk](mailto:info@asbestosforum.org.uk)

[www.asbestosforum.org.uk](http://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](mailto:mail@apil.org.uk)

[www.apil.org.uk](http://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](http://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](http://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, support groups and a team of clinical nurse specialists throughout the UK.

### **Veterans UK**

Helpline **0808 1914 218** (Mon to Fri, 8am to 5pm)

Email **veterans-uk@mod.gov.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**

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

Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

### Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)

Email **[nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)**

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

Offers a variety of services to people affected by cancer in Northern Ireland.

### Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)

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

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.



## Tenovus

Helpline **0808 808 1010** (Mon to Fri, 9am to 5pm, and Sat and Sun 10am to 1pm)

Email **info@tenovuscancercare.org.uk**

**www.tenovuscancercare.org.uk**

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## 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, for people experiencing feelings of distress or despair.

## Financial support or legal advice and information

### Advice NI

Helpline **0800 915 4604**

Email **advice@adviceni.net**

Provides advice on a variety of issues including financial, legal, housing and employment issues.

### Benefit Enquiry Line Northern Ireland

Make the Call Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)

Textphone **028 9031 1092**

**[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Carer's Allowance Unit

Tel **0800 731 0297**

Textphone **0800 731 0317** (Mon to Fri, 8am to 6pm)

**[www.gov.uk/carers-allowance-unit](http://www.gov.uk/carers-allowance-unit)**

Manages state benefits in England, Scotland and Wales.

You can apply for benefits and find information online or through its helplines.

### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

#### England

Helpline **0800 144 8848**

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

#### Scotland

Helpline **0800 028 1456**

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

## Wales

Helpline **0800 702 2020**

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

## Civil Legal Advice

Helpline **0345 345 4345** (Mon to Fri, 9am to 8pm,  
and Sat, 9am to 12.30pm)

Textphone **0345 609 6677**

**[www.gov.uk/civil-legal-advice](http://www.gov.uk/civil-legal-advice)**

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

## GOV.UK

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

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

## Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250** (Mon, Tue, Wed and Fri, 9am to 5pm,  
and Thu, 10am to 5pm)

Textphone **028 9031 1092**

**[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

## NiDirect

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

Has information about benefits and public services in Northern Ireland.

## LGBT-specific support

### LGBT Foundation

Helpline **0345 330 3030** (Mon to Fri, 9am to 9pm)

Email **helpline@lgbt.foundation**

**www.lgbt.foundation**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

## Support for carers

### Carers Trust

Tel **0300 772 9600**

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 Fri, 9am to 6pm)

Tel (Northern Ireland) **028 9043 9843**

**www.carersuk.org**

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

## Support for older people

### Age UK

Helpline **0800 678 1602** (Daily, 8am to 7pm)

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

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

## Advanced cancer and end-of-life care

### Marie Curie

Helpline **0800 090 2309** (Mon to Fri, 8am to 6pm, and Sat, 11am to 5pm)

**[www.mariecurie.org.uk](http://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, Tue to Thu, 9.30am to 8pm, and Sat and Sun, 10am to 2pm)

Email **[helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)**

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

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

## Cancer registries

### The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

#### National Disease Registration Service (NDRS)

[www.digital.nhs.uk/ndrs/patients](http://www.digital.nhs.uk/ndrs/patients)

#### Scotland – Public Health Scotland (PHS)

[www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview](http://www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview)

#### Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 0292 010 4278

[www.phw.nhs.wales/wcisu](http://www.phw.nhs.wales/wcisu)

#### Northern Ireland Cancer Registry

Tel 0289 097 6028

[www.qub.ac.uk/research-centres/nicr/AboutUs/Registry](http://www.qub.ac.uk/research-centres/nicr/AboutUs/Registry)



## Disclaimer

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

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editor, Dr David Gilligan, Consultant Clinical Oncologist.

With thanks to: Dr Jaishree Bhosle, Consultant Medical Oncology; Mr Tom Cecil, Consultant Colorectal Surgeon; Lorraine Creech, Head of Nursing Mesothelioma UK; Roger Maddocks, Irwin Mitchell Solicitors; Mr Apostolos Nakas, Thoracic Oncology Surgeon; and Samantha Westbrook, Peritoneal 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 [informationproductionteam@macmillan.org.uk](mailto:informationproductionteam@macmillan.org.uk)

## Sources

Below is a sample of the sources used in our mesothelioma information. If you would like more information about the sources we use, please contact us at [informationproductionteam@macmillan.org.uk](mailto:informationproductionteam@macmillan.org.uk)

Baas P et al. Malignant pleural mesothelioma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology* 26 (Supplement 5): v31–v39. 2015. Available from: [pubmed.ncbi.nlm.nih.gov/26223247](http://pubmed.ncbi.nlm.nih.gov/26223247) Thomas A et al. Mesothelioma *BMJ Best Practice*. 2019. Woolhouse I et al. British Thoracic Society Guideline for the investigation and management of malignant pleural mesothelioma. *Thorax* 2018. Available from: [thorax.bmj.com/content/73/Suppl\\_1/i1](http://thorax.bmj.com/content/73/Suppl_1/i1)



# Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £  
(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support  
OR debit my:  
Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

## Do not let the taxman keep your money

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

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

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.

If you would rather donate online  
go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)



Registered with  
**FUNDRAISING  
REGULATOR**



Please cut out this form and return it in an envelope (no stamp required) to: Supporter donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

**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.**

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

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call **0808 808 00 00** 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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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Patient Information Forum