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 about treatments for both pleural and peritoneal mesothelioma. There is also information about managing symptoms and what support is available.

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 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

At the end of the booklet, there are details of other organisations that can help.

Quotes

In this booklet, we have included a quote from someone who has had cancer, which you may find helpful. This is from someone who has chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using 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, easy read, Braille, large print, interactive PDFs and translations. To order these, visit macmillan.org.uk/otherformats or call 0808 808 00 00.

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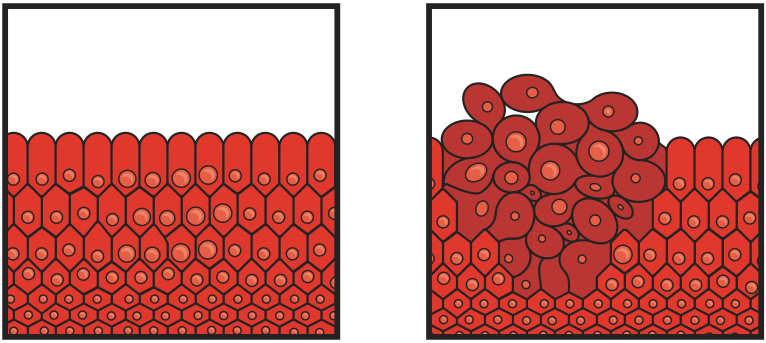
What is cancer?

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.

Abnormal 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 is called a benign tumour. It 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 is called a malignant tumour. It 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. 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.

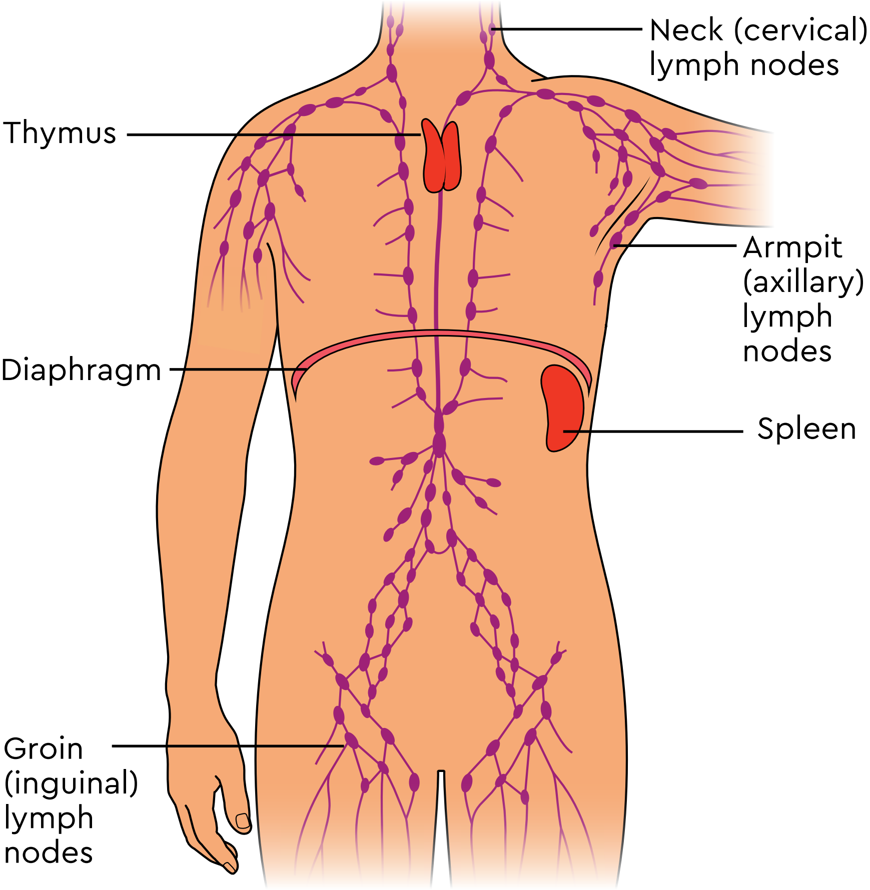
The lymphatic system

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.

Mesothelioma can spread to the lymph nodes in the chest.

Lymph nodes in the body



What is mesothelioma?

In the UK, more than 2,700 people are diagnosed with mesothelioma (pronounced mee-so-thee-lee-oh-muh) each year.

Mesothelioma is a cancer of the mesothelium. The mesothelium 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 in the tummy (abdomen) is called the peritoneum.

The mesothelium is made up of mesothelial cells. If these cells develop abnormally, they can develop into cancer called malignant mesothelioma. Malignant mesothelioma is usually just called mesothelioma.

When mesothelioma affects the chest, it is called pleural mesothelioma. When it affects the abdomen, it is called peritoneal mesothelioma. Pleural mesothelioma is much more common.

Pleural mesothelioma

The lungs sit in the chest, on either side of the heart. When you breathe air into your lungs, they supply oxygen to your body.

The lungs are covered by a lining (membrane) called the pleura. The pleura is made up of 2 layers:

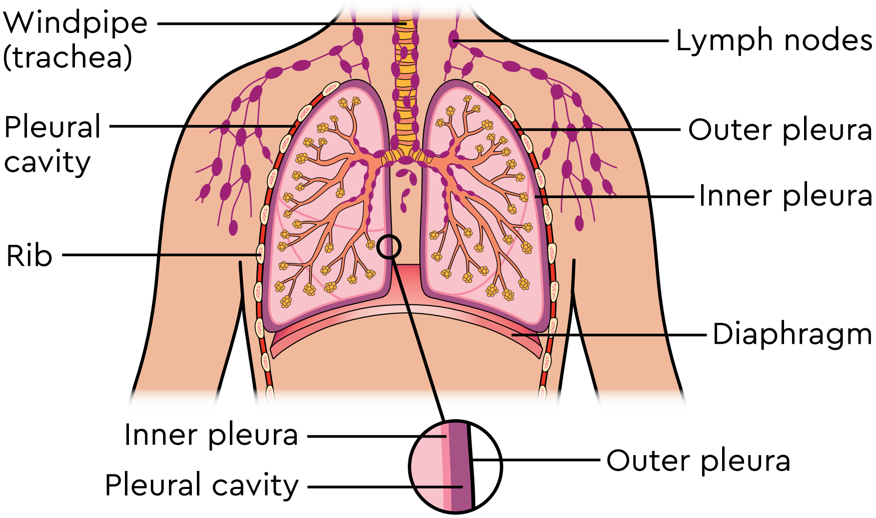
- The inner layer covers the lungs.
- The outer layer lines the ribcage and a sheet of muscle called the diaphragm. The diaphragm separates the chest from the tummy.

The space between the 2 layers is called the pleural cavity. The pleural cavity has a small amount of fluid in it. This fluid acts as a lubricant. This allows the lungs to move in and out smoothly so you can breathe easily.

Pleural mesothelioma starts as small lumps (nodules) that grow and spread throughout the pleura. As these lumps grow together, the pleura becomes thicker. This means the lungs cannot move as easily and you become breathless. Fluid may also collect between the 2 layers of the pleura. This is called a pleural effusion.

We have more information about pleural effusion on our website. Visit macmillan.org.uk/pleural-effusion

Structure of the lungs and pleura



Peritoneal mesothelioma

The organs in the tummy (abdomen) are covered by a lining. This lining (membrane) is called the peritoneum. It has an inner and outer layer:

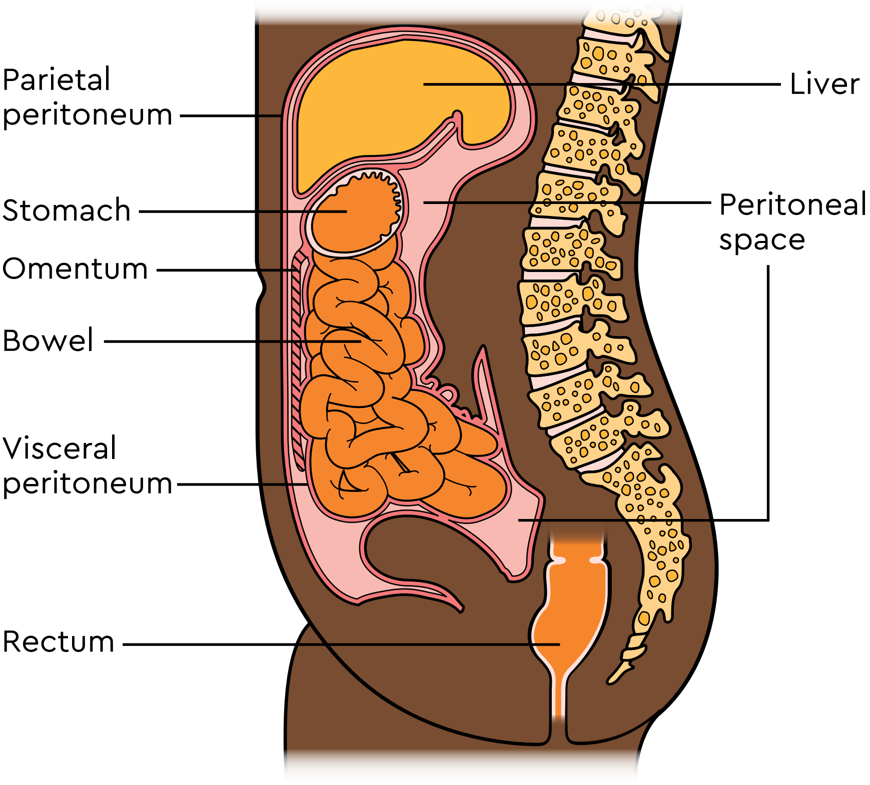
- The inner layer covers the organs in the abdomen. This is called the visceral peritoneum.
- The outer layer lines the abdominal wall. This is called the parietal peritoneum.

The peritoneum helps protect the organs in the abdomen and keeps them in place.

Mesothelioma can cause the layers of the peritoneum to thicken. It can also cause fluid to build up between the 2 layers. This is called ascites.

We have more information about ascites on our website. Visit macmillan.org.uk/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. The different types include:

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

Knowing the type of cell that is affected 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 – this is called pericardial mesothelioma
- testes – this is called testicular mesothelioma.

Finding out you have mesothelioma

Being diagnosed with mesothelioma can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis might have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with mesothelioma. We have more information on our website about the possible causes, risk factors, symptoms and diagnosis of mesothelioma. Visit macmillan.org.uk/mesothelioma

Waiting for treatment to start can be a difficult time. You may be worried about telling people and the treatment options you have. You might choose to spend some time reading about the cancer, or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on the Macmillan Support Line. They will be able to talk to you about what has happened and any worries you have.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.

Staging of mesothelioma

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What is staging?

The stage of pleural mesothelioma refers to its size and the thickness of the pleura. The stage also tells you if the cancer has spread to the lymph nodes, and beyond the area of the body where it first started. Knowing the stage of the cancer helps you and your doctors decide on the best treatment for you.

There are 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 to another part of the body. This is called metastasis. 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.

Staging of pleural mesothelioma

The staging system often used for pleural mesothelioma is written by the International Association for the Study of Lung Cancer (IASLC). It is based on the TNM system.

Stage 1

The cancer is limited to the pleura, in 1 side of the chest. It is 12mm or less in thickness. The cancer has not spread to the lymph nodes.

Stage 2

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

Or the cancer is 12mm thick or less, and has grown into the tissue beneath the pleura. The cancer has not spread to the lymph nodes.

Or the cancer is more than 12mm thick but less than 30mm, and may or may not have spread into the tissue beneath the pleura. It has not spread to the lymph nodes.

Stage 3

Stage 3 pleural mesothelioma is divided into Stage 3a and Stage 3b.

Stage 3a

The cancer is up to 12mm thick and has spread to lymph nodes on the other side of the chest (N2).

Or the cancer is between 12mm and 30mm thick, and may also have spread into the tissue beneath the pleura. It has also spread to lymph nodes nearby (N1) or further away (N2).

Or the cancer is 30mm or more, and is involving tissue beneath the pleura. It may or may not have spread to lymph nodes nearby (N1) or further away (N2).

Stage 3b

The cancer is any thickness and has spread further into the chest wall.

For example, it may have affected the ribs, the oesophagus or the windpipe (trachea).

It may also have spread through the lining of the heart, or through the diaphragm.

It may or may not have spread to nearby lymph nodes, or lymph nodes further away on the other lung.

Stage 4

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

Staging of peritoneal mesothelioma

There is no specific staging system for peritoneal mesothelioma. But your cancer team may sometimes use the Peritoneal Cancer Index (PCI) system.

This includes:

- 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 in specialist centres. You can ask your cancer doctor for more information if you have any questions.

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. 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 may depend on which type of mesothelioma you have. It may include immunotherapy, chemotherapy and radiotherapy.

Surgery is sometimes used to treat peritoneal mesothelioma. Surgery is rarely used to treat pleural mesothelioma, but may be used to help control symptoms.

You may also be offered treatment as part of a clinical trial.

How your treatment is planned

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

Multidisciplinary team (MDT) meeting

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

The MDT reviews 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.

If you are diagnosed with mesothelioma, your care and treatment are usually discussed by a local MDT first. Then you will be referred to a specialist mesothelioma MDT.

The MDT will usually include the following professionals:

- Chest physician – a doctor experienced in lung disease (if you have pleural mesothelioma).
- Medical oncologist – a doctor who uses chemotherapy and other anti-cancer drugs to treat people with cancer.
- 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) or abdominal surgery (if you have peritoneal mesothelioma).
- 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 MDT 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 consider different factors when planning your treatment and care. These include the type and stage of the 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 make the right decision for you.

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

The benefits and disadvantages of treatment

Many people feel worried about having cancer treatments. This may be because they are concerned about possible side effects. But these can usually be controlled with medicines. Treatment can be given for different reasons, and the potential benefits will vary depending on your situation.

For most people with pleural and peritoneal mesothelioma, the aim of treatment is to slow the growth of the cancer. This can help improve symptoms and may help improve quality of life. But for some people, the treatment will have no effect on the cancer. This means they may get the side effects of the treatment with little benefit.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss 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.

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 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 cancer 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 cancer 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 with 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 on our website. Visit macmillan.org.uk/second-opinion

Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about clinical trials on our website. Visit macmillan.org.uk/clinical-trials

Taking part in a clinical 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.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

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Treatment for pleural mesothelioma

Treatment is given to help control symptoms and to slow the growth of pleural mesothelioma.

Treatments may include:

- immunotherapy
- chemotherapy
- radiotherapy.

Surgery is sometimes used to help control symptoms. You may also have other treatments to help control symptoms. These are called supportive therapies.

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.

The immunotherapy drugs used to treat pleural mesothelioma are nivolumab and ipilimumab. They are usually given in combination. These drugs are also called checkpoint inhibitors or CPIs. You have them as a drip into the vein (intravenous).

Immunotherapy is usually given as a first treatment for pleural mesothelioma. But sometimes nivolumab may be offered on its own to some people who have already had chemotherapy and need further treatment.

We have more information about immunotherapy on our website. Visit macmillan.org.uk/immunotherapy

Side effects of immunotherapy

Different checkpoint inhibitor drugs can cause different side effects.

Your cancer team will give you information about possible side effects before you start treatment. You may get some of the side effects they mention, but you are unlikely to get all of them.

Your cancer team will monitor you regularly during and after treatment. They can give you drugs to help control some side effects and advice on how to manage them. It is important to take any drugs exactly as explained. This means they will be more likely to work for you.

We have more information about immunotherapy drugs and their side effects on our website. Visit macmillan.org.uk/treatments-and-drugs

Immune related side effects

Immunotherapy drugs can attack healthy tissue and make the immune system react. This can cause inflammation in different organs of the body. Sometimes this causes very serious side effects called immune related side effects.

Your doctor, nurse or pharmacist will explain the possible side effects and what to do if you have any. It is very important to know about them so you can contact the hospital straight away. You will need to be treated quickly. Do not try to treat this type of side effect yourself.

Some of the organs or parts of the body that might be affected include:

- the liver
- the lungs
- the bowel
- the kidneys
- glands that make certain hormones
- the joints
- the skin.

If you think you have any of these side effects, contact the hospital straight away on the 24-hour number you have been given.

Immune system side effects can start in the first weeks or months of treatment. But sometimes they happen up to 2 years after treatment has finished.

Sometimes your doctor may delay treatment until side effects improve. If you have serious side effects, your doctor may advise stopping the treatment. They can talk to you about other possible treatment options.

Contacting the hospital

Your doctor, nurse or pharmacist will give you 24-hour contact numbers for the hospital. If you feel unwell or need advice, you can call at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

Sometimes side effects can become serious very quickly. Always contact the hospital straight away for advice. Always have your patient alert card with you during treatment and after treatment ends.

Diarrhoea or tummy pain

You may have diarrhoea or tummy (abdominal) pain. This treatment can also cause inflammation of the bowel (colitis), which can be very serious.

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

Contact the hospital straight away on the 24-hour number if you have any of the following symptoms during treatment, or after treatment ends:

- You have diarrhoea 4 or more times in a day.
- Your stoma is working more than is usual for you.
- You have uncomfortable tummy cramps.
- You have diarrhoea at night.
- Your temperature is over 37.5°C.
- There is blood or mucus in your stool.

You may need to go into hospital to have fluids through a drip or treatments such as steroids.

Skin changes

This treatment may cause inflammation in the skin. This is usually mild, but if it is not treated it can become serious. You may need creams, steroids or other medicines to treat skin problems.

If you notice skin changes during treatment, or after treatment ends, contact the hospital on the 24-hour number as soon as possible.

Skin changes can include:

- a rash or bumps on the skin
- dry or itchy skin
- patches of white or paler skin.

To protect your skin from the sun, use suncream with an SPF of at least 30. SPF stands for sun protection factor. Cover up with clothing and a hat.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms:

- a rash that is spreading
- blistering or peeling skin
- flu-like symptoms, such as a high temperature and joint pain.

These symptoms can be a sign of a serious skin reaction that needs to be treated immediately in hospital.

Low number of white blood cells

This treatment can reduce the number of white cells in your blood. These cells fight infection. If you have any signs of an infection, tell your doctor, nurse or pharmacist. These signs include:

- a cough
- a sore throat
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature.

Effects on the lungs

This treatment can cause inflammation of the lungs. This is called pneumonitis. Contact the hospital straight away on the 24-hour number if you notice any of these changes during treatment or after it ends:

- breathlessness
- a cough that does not go away
- wheezing
- a fever, with a temperature over 37.5°C.

You should also tell them if any existing breathing problems get worse. You may have tests to check your lungs. You may need steroids or other treatments.

Effects on the liver

This treatment can cause liver inflammation and may affect how your liver works. This is called hepatitis. You will have regular blood tests to check this. If the blood tests show liver changes, you may have steroids.

Sometimes liver changes can be serious. Contact the hospital straight away on the 24-hour number if you have any of these symptoms during treatment or after it finishes:

- yellow skin or eyes
- feeling very sleepy
- dark urine (pee)
- unexplained bleeding or bruising
- pain in the right side of your tummy (abdomen)
- loss of appetite.

Muscle and joint pain

This treatment can cause sore or weak muscles. Your joints may also be stiff, sore or swollen (arthritis). If you already have problems with joint pain, this may become worse. Contact the hospital on the 24-hour number if you have any of these symptoms during treatment or after it ends:

- new or worsening aches or pains
- new or worsening stiffness in a joint
- swollen joints.

You may need steroids or other treatments, such as painkillers.

Raised blood sugar levels

This treatment may raise your blood sugar levels and increase the risk of diabetes.

You will have regular blood tests to check this.

Signs of raised blood sugar include:

- feeling thirsty
- needing to pass urine (pee) more often than usual
- feeling more tired than usual.

Contact the hospital on the 24-hour number if you have these symptoms during treatment or after it ends.

If you already have diabetes, your blood sugar levels may be higher than usual. You may need advice and support from your GP or diabetes team about managing this.

Other side effects of immunotherapy

There may be other side effects of immunotherapy.

Feeling sick

Your doctor, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids.

If you continue to feel sick, or if you are sick (vomit) 1 to 2 times in 24 hours, contact the hospital on the 24-hour number as soon as possible. They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

We have more information about feeling sick on our website. Visit macmillan.org.uk/nausea-vomiting

Feeling tired (fatigue)

Feeling tired is a common side effect of this treatment. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can help you feel less tired.

Sometimes tiredness is caused by this treatment affecting glands that produce hormones. If your hormone levels are low, you may need hormone replacement drugs.

Contact your cancer team or hospital if either of these things happen during treatment or after it ends:

- your tiredness gets worse
- you feel weak or shaky.

If you feel sleepy, do not drive or use machinery.

We have more information about feeling tired on our website. Visit macmillan.org.uk/fatigue

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. It may also help with symptoms such as pain and breathlessness. Your doctor will tell you whether 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 1 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.

How many cycles you have will depend on:

- the stage of the cancer
- how well the cancer is responding to treatment
- the side effects of the treatment.

Having cancer treatment into a vein

Chemotherapy drugs

The most commonly used drugs to treat pleural mesothelioma are pemetrexed (Alimta®) with carboplatin or cisplatin. 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 and folic acid. These help to reduce the side effects of treatment. You may also be given other medicines to take at home.

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

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, nurse or pharmacist will explain what to expect.

We explain some of most common side effects of pemetrexed, cisplatin and carboplatin 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, nurse or pharmacist about any side effects.

We have more information about chemotherapy drugs and their side effects on our website. Visit macmillan.org.uk/treatments-and-drugs

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If your white blood cell count is low, you may be more likely to get an infection. A low white blood cell count is 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. If you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

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

Your white blood cell count 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, brown or purple spots that may look like a rash – these spots can be harder to see if you have black or brown skin.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood 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 feel:

- very low in energy
- breathless
- dizzy and light-headed.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia. 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, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids.

If you continue to feel sick, or if you are sick (vomit) 1 to 2 times in 24 hours, contact the hospital on the 24-hour number as soon as possible. They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

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.

Contact the hospital straight away on the 24-hour number, if:

- a sore mouth or throat affects how much you can drink or eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

The hospital can give you advice, and mouthwash or medicines to help with the pain or to treat any infection. Follow their advice and make sure you:

- drink plenty of fluids
- avoid alcohol and tobacco
- avoid food or drinks that irritate your mouth and throat.

Diarrhoea

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

If you are passing loose stools 3 or more times a day and this is not normal for you, contact the hospital as soon as possible on the 24-hour number. Follow the advice they give you about:

- taking anti-diarrhoea medicines
- drinking enough fluids to keep you hydrated and to replace lost salts and minerals
- any changes to your diet that might help.

They might also ask you for a specimen of your stool to check for infection.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment may affect the nerves in your fingers and toes. This can cause numbness, tingling or pain in your hands or feet. This is called peripheral neuropathy. You might find it hard to do fiddly tasks such as fastening buttons or tying shoelaces.

If you have these symptoms, always tell your doctor, nurse or pharmacist. They sometimes need to change the drug or the dose of the drug. The symptoms usually improve slowly after treatment ends. But for some people, the symptoms continue and are a long term side effect of treatment.

Hearing changes

This treatment may cause hearing changes, including hearing loss. You may have ringing in the ears. This is called tinnitus. You may also become unable to hear some high-pitched sounds.

Hearing changes may get better after this treatment ends. But this does not always happen. If you notice any changes in your hearing, tell your doctor, nurse or pharmacist.

Radiotherapy for pleural mesothelioma

Radiotherapy uses high-energy rays to treat cancer. 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 or swelling.

Sometimes it may be given as part of a clinical trial.

You may only need 1 or 2 treatments. Or you may have a course of 5 treatments.

Radiotherapy is carefully planned by a team of experts. They will plan your treatment so it does as little harm as possible to normal cells.

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

We have more information about the side effects of radiotherapy on our website. Visit macmillan.org.uk/side-effects-radiotherapy

Planning your radiotherapy treatment

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. During the scan, you need to lie in the position that you will be in for all your radiotherapy treatments.

Your radiotherapy team uses information from this scan to plan the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They are made in the same way as a tattoo. The marks help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. If you are worried about them or already have a tattoo in the treatment area, tell your radiographer. They can discuss this with you.

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, they 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

The side effects of radiotherapy for pleural mesothelioma are usually mild. This is because you usually only have a small number of treatments.

Your doctor, radiographer or nurse will tell you what to expect. Tell them about any side effects you have. There are often things that can be done to help.

Feeling tired is a common side effect of radiotherapy. Try to pace yourself and plan your day so you have time to rest. Gentle exercise can give you more energy – for example, short walks, if you are able to. You can also ask people to help with everyday jobs if you are feeling too tired.

We have more information about tiredness:

- in our booklet and audiobook Coping with fatigue (tiredness)
- on our website at macmillan.org.uk/fatigue

Some people may feel sick (nausea). This is usually mild. Tell your radiographer, nurse or doctor if you feel sick. They can give you anti-sickness drugs to help. We have more information about nausea on our website. Visit macmillan.org.uk/nausea-vomiting

Surgery for pleural mesothelioma

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

The most common procedure is placing a drain. This is to drain fluid that has built up around the lung. This can help with symptoms such as breathlessness. A procedure called pleurodesis can be done to help stop the fluid from building back up again. We have more information online at macmillan.org.uk/pleural-effusion

Radical surgery to remove the mesothelioma is not usually done. Recent studies looked at the benefits versus the risks of surgery to remove mesothelioma. The results showed that for most people the risks of surgery outweigh the benefits. Your cancer doctor can explain more about this to you.

Treating peritoneal mesothelioma

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Treatment for peritoneal mesothelioma

For most people, treatment is given to help control symptoms and slow the growth of peritoneal mesothelioma. The treatments you may be offered depend on many different things. These include:

- the type of mesothelioma
- the stage of the mesothelioma
- your general fitness
- any other illnesses you may have.

Treatments may include:

- immunotherapy
- chemotherapy
- surgery
- other treatments that are sometimes called supportive therapies.

Immunotherapy for peritoneal 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.

You may be offered immunotherapy to treat peritoneal mesothelioma. There are different types of immunotherapies that work in different ways.

The most common immunotherapy drugs used for peritoneal mesothelioma are nivolumab and ipilimumab. They are usually given together. Your cancer team will explain if this treatment is suitable for you.

We have more information about the possible side effects of nivolumab and ipilimumab online. Visit macmillan.org.uk/treatments-and-drugs

How immunotherapy is given

Immunotherapy drugs for peritoneal mesothelioma are given into a vein (intravenously). Each drug is usually given over 30 minutes. Nivolumab is usually given once every 3 weeks. Ipilimumab is usually given once every 6 weeks.

How often and how long you have immunotherapy for depends on:

- the type of immunotherapy you are given
- how your body reacts to the treatment
- whether the immunotherapy is working effectively.

Your cancer team will explain how often you will have them.

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 chemotherapy to help slow the growth of peritoneal mesothelioma and control symptoms. This may be offered if immunotherapy is not suitable for you, or if you have already had immunotherapy. Your doctor will tell you whether chemotherapy is right 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 1 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 depends on:

- the stage of the cancer
- how well the cancer is responding to treatment.

Chemotherapy drugs

The most commonly used drugs to treat peritoneal mesothelioma are pemetrexed (Alimta®) 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.

The most common side effects of pemetrexed and cisplatin are described here.

We have more information about chemotherapy drugs and their side effects on our website.
Visit macmillan.org.uk/treatments-and-drugs

Surgery for peritoneal mesothelioma

A small number of people with peritoneal mesothelioma may be offered surgery. This is called complete cytoreductive surgery (CRS) and hyperthermic intraperitoneal chemotherapy (HIPEC).

Whether this treatment is suitable for you depends on many different things. These include:

- the type of mesothelioma
- the location of the mesothelioma in the tummy area (abdomen)
- whether the surgeon thinks it is possible to completely remove the mesothelioma
- your general fitness.

The operation will be done by a surgeon who is experienced in 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.

The surgeon will remove most of your peritoneum. This is called a 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 can 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.

During the surgery, the surgeon will remove as much of the tumour as they can see. Then they will put a heated chemotherapy drug directly into your tummy. This is called hyperthermic intraperitoneal chemotherapy (HIPEC).

Chemotherapy into the abdomen (HIPEC)

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 HIPEC will target the area and aim to remove any loose mesothelioma cells. The chemotherapy is left in place for around 60 minutes to give it time to work. It is then washed out.

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

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Follow-up

After your treatment has finished, your cancer team, 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 meet with a physiotherapist if you need help with your mobility or advice on breathing exercises.

Who can help?

Many people are available to help you and your family.

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

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

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer.

Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you are 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.

Specialist help is also 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 the Macmillan Support Line can tell you more about counselling and can let you know about services in your area.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm. ☎

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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.

Managing symptoms of pleural mesothelioma

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

Breathlessness

Breathlessness is a common symptom of pleural mesothelioma. It is often caused by a build-up of fluid between the 2 layers of the pleura. The pleura are the linings (membranes) that cover the lungs. This build-up of fluid is called a pleural effusion.

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 breathing easier.

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

Your doctor may give you medicines to help with breathlessness. This might be a low dose of a painkiller called morphine, or drugs to help 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 oxygen at home if it is suitable for you.

Coughing

Coughing is also common with 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. You may also find it helpful to:

- sleep in a different position – such as 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.

We have more information about breathlessness:

- in our booklet and audiobook Managing breathlessness
- on our website at macmillan.org.uk/breathlessness

Pleural effusion

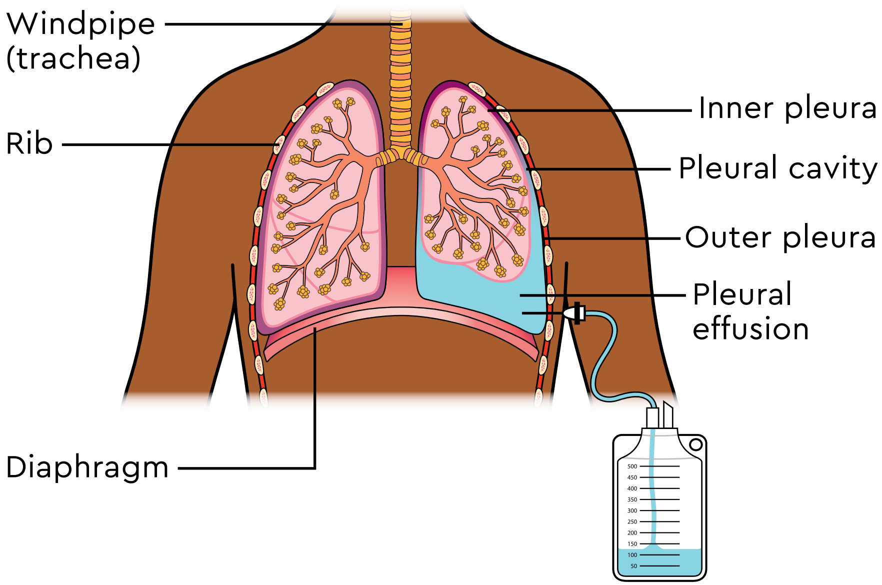
A build-up of fluid between the 2 layers of the pleura is called a pleural effusion. If you have a pleural effusion, your doctor usually puts a tube in the side of your chest to drain the fluid.

Before they do this, they clean the skin with an antiseptic. They then give you an injection of local anaesthetic to numb the area. You will not feel any pain during the procedure. Sometimes it is done under general anaesthetic, which means you will be asleep.

Your doctor makes a very small cut in the chest. They insert the chest drain into the space where the fluid is collecting. Sometimes they use an ultrasound scan to help guide the tube into the correct position. When the tube is in, they attach the chest drain to a bag or bottle for the fluid to drain into.

We have more information about chest drains on our website. Visit macmillan.org.uk/pleural-effusion

Pleural effusion with drainage



Preparing a pleural catheter

Indwelling pleural catheter (IPC)

To help drain the fluid, you can have a small tube inserted into the chest. This is called an indwelling pleural catheter (IPC). It is usually put in under local anaesthetic. Sometimes it is put in under general anaesthetic.

The tube is soft and flexible. It is about the size of a straw. One end sits in the chest where the fluid collects. The other end passes through the skin. It has a valve that can be opened and closed.

The drain can stay in place when you go home. You can drain the fluid whenever it starts to build up again around the lung. This might be once a day or every few days, depending on how quickly it builds up.

The tube can be connected to a bottle for the fluid to drain into. You can then disconnect the bottle and empty it. The nurses will show you how to use the drain. When you are not using it, the tube is not noticeable. It will be under your clothes and should not affect your daily activities.

Managing symptoms of peritoneal mesothelioma

Different treatments can control 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
- feel sick
- feel breathless.

Doctors can treat ascites by putting in a small tube to drain 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. 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 stitches and covered with a dressing.

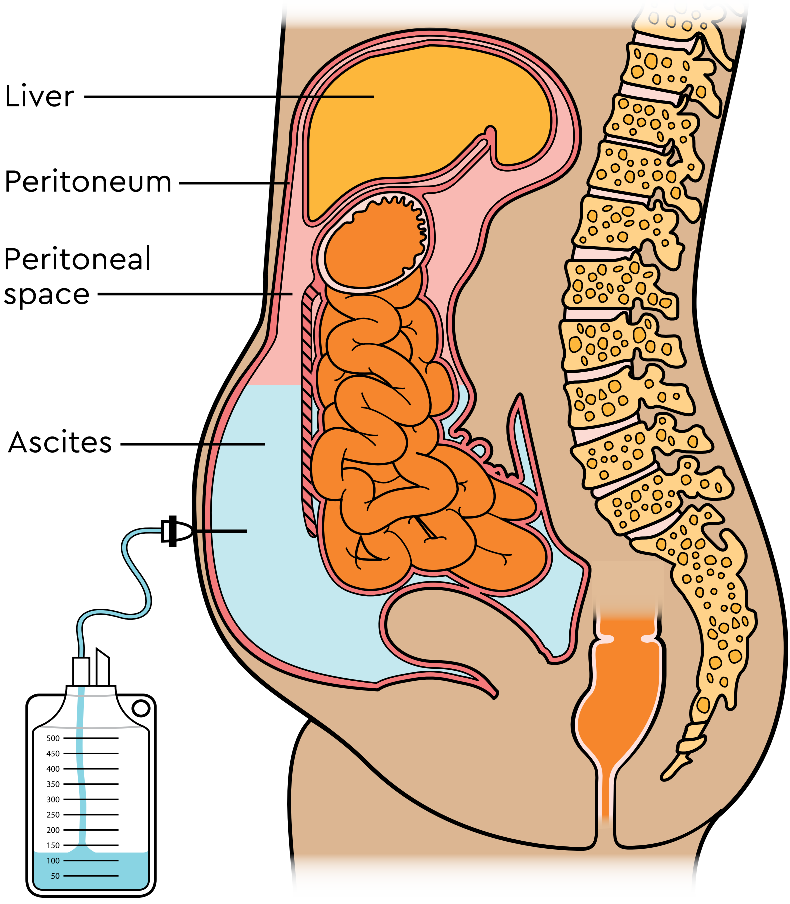
The tube is usually taken out after the fluid is drained. But sometimes it stays in for a few days. It depends on the amount of fluid that needs to be drained.

If the fluid builds up again, you may need it drained more than once. If it keeps building up 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 or nurse will give you more information about this.

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

We have more information about ascites at macmillan.org.uk/ascites

Side view of the abdomen showing drainage of ascites



Blocked bowel (bowel obstruction)

Sometimes, peritoneal mesothelioma causes the bowel to become blocked.

Symptoms of a blocked bowel may include:

- pain that comes on suddenly
- being unable to have a bowel movement (not able to poo) or being constipated
- feeling bloated or having a swollen tummy
- sickness
- feeling out of breath.

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

Managing other symptoms

There are ways to manage other symptoms of mesothelioma.

Pain

Pain is a common symptom of mesothelioma. Tell your doctors or specialist nurse if you have pain so they can treat it early. There are different ways to manage pain depending on the cause.

Your cancer team will assess the pain and usually give you painkillers to help.

We have more information about managing cancer pain on our website. Visit macmillan.org.uk/pain

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 and diclofenac
- 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.

Radiotherapy can also be used to help manage pain in some situations.

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 or nurse 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 ways to control it. This might include a specialised procedure called a nerve block.

We have more information about managing pain in our booklet and audiobook Managing cancer pain.

Night sweats

Mesothelioma can cause some people to sweat a lot at night. This can be distressing, especially if you wake up 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 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.
- Use natural fibre bed sheets and pyjamas, and have spare ones nearby so you can change them 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 meals more often. 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 pharmacies, 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. 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 and audiobook Eating problems and cancer and on our website. Visit macmillan.org.uk/eating-problems

Tiredness

Many people with mesothelioma feel tired and have less energy. This may be because of the cancer, or 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 some goals. These goals could include:

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

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

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 about difficulty sleeping on our website. Visit macmillan.org.uk/trouble-sleeping

Tiredness is also a common symptom of depression. If you think you are depressed, talk to your doctor or nurse. Talking about your feelings with a professional counsellor can also help.

We have more information about tiredness:

- in our booklet and audiobook Coping with fatigue (tiredness)
- on our website at macmillan.org.uk/fatigue

Complementary therapies

Some people find that complementary therapies may help them to cope with symptoms and side effects. These may include acupuncture, massage, aromatherapy and relaxation techniques. 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 may need to avoid some complementary therapies during cancer treatments and for a short time after.

We have more information in our booklet and audiobook Cancer and complementary therapies and on our website. Visit macmillan.org.uk/complementary-therapies

Your feelings and relationships

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Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions:

- in our booklet and audiobook How are you feeling? The emotional effects of cancer
- on our website at macmillan.org.uk/emotions

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There are also other ways we can help you.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

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 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 or starting a new hobby.
- 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.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.

We have more information in our booklets:

- Healthy eating and cancer – this is also available as an audiobook
- Physical activity and cancer
- Cancer and complementary therapies – this is also available as an audiobook.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information in our booklets:

- Talking about cancer
- Cancer and relationships: support for partners, families and friends – this is also available as an audiobook.

We also have more information about relationships on our website. Visit macmillan.org.uk/relationships

> **"I used the Macmillan Support Line and Online Community. It was lovely to have someone who would listen to all the things that sometimes you're afraid to say to the people closest to you. It helped me put things in perspective."**
>
> David, diagnosed with prostate cancer

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 can support the person with cancer by listening and talking with them.

We have more information about supporting someone in our booklet and audiobook Talking with someone who has cancer – also available as an audiobook.

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 with cancer – also available as an audiobook.
- on our website at macmillan.org.uk/carers

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet and audiobook Talking to children and teenagers when an adult has cancer.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

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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 this help:

- benefits paid by the Department for Work and Pensions (DWP)
- compensation for you or your spouse due to asbestos exposure.

If you have been diagnosed with mesothelioma, you should consider these types of financial help.

Types of asbestos exposure

There are 3 main types of asbestos exposure:

- Occupational exposure is when you are exposed to asbestos while working. This could be from your current employer or a past employer.
- Secondary exposure is when you are exposed to asbestos through another person, such as a spouse, parent or sibling. For example, this may happen if you have handled their clothing and it had asbestos on it.
- Environmental exposure is when you are exposed to asbestos in the environment, such as in air, soil or water. This might be in a public or private area.

Benefits

Many people think that benefits paid by the government are means tested. This means the amount of savings and income you have determines whether you can get them.

It is important to remember that some benefits are means tested, but many are not. A benefits adviser or your solicitor will be able to tell you more about the benefits you can claim.

You may be able to get more information by talking with one of our money advisers through the Macmillan Support Line on 0808 808 00 00.

Local asbestos support groups may also offer advice and information about benefits. You can get information about support groups from Asbestos Victims Support Group Forum UK or Mesothelioma UK.

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 are unable to work. You can still get it if you are able to do some work (permitted work). Get advice before working and claiming ESA.

You can call 0808 808 00 00 to speak to a Macmillan money adviser about these types of benefits. We also have more detailed information about SSP and ESA in our booklet and audiobook Help with the cost of cancer, and on our website at macmillan.org.uk/benefits

Disability benefits

Disability 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. If you live in Scotland, PIP has been replaced by the Adult Disability Payment (ADP).

Attendance Allowance (AA) is a benefit for people who are at or above State Pension age. If you live in Scotland, you may get the Pension Age Disability Payment (PADP) instead of AA.

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 are likely to have less than 12 months to live.

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. If you live in Scotland, there is no set timeframe for how long you are expected to live to be classed as terminally ill.

We have more detailed information about disability benefits and special rules in our booklet Help with the cost of cancer.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Industrial Injuries Disablement Benefit

You can claim Industrial Injuries Disablement Benefit (IIDB) if a job, training scheme or training course caused you to have 1 of the following:

- a disease, including cancer
- an accident.

This is an important benefit for people with mesothelioma or other asbestos-related illnesses.

You may get this benefit if the mesothelioma could have been caused by exposure to asbestos dust at work. You do not need to have worked with asbestos to get this benefit. You only need to have been exposed to asbestos dust while working for an employer.

This benefit also applies if you are now retired or worked in other countries for a UK company.

If you were self-employed when you were exposed to asbestos, you cannot usually claim for IIDB. There may be some rare cases where it may be possible – for example, if you are an agency worker. But this will depend on your contract when you were self-employed. You can speak to your solicitor for advice about this.

Before making a claim for IIDB, you should always get advice from a specialist solicitor. It is very important that the information on the benefit application form is filled in correctly. Incorrect information may affect your claim for IIDB, or other compensation claims.

You will need to give information about where and how you were exposed to asbestos. A specialist solicitor can often help you investigate how you may have been exposed.

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

People with mesothelioma are entitled to the maximum IIDB rate. If you are given this benefit, you may also be entitled to other benefits. If you are awarded IIDB because of mesothelioma, you will also be considered for Constant Attendance Allowance (CAA). CAA overlaps with other disability benefits, but the application process can be slow. This is because CAA has no fast-track system for people with a terminal illness.

You can get more information from a specialist solicitor or welfare rights adviser, and by contacting Citizens Advice or Advice NI.

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. A lump sum means you get the total amount all at once. If you have mesothelioma that was not caused through employment, you may still be able to get the payment. You may also be able to get the payment if you were exposed to asbestos while working in other countries for a UK company.

You can apply for the lump sum through different schemes. The DWP will work out which scheme the payment will be made from.

The different schemes are:

- the Diffuse Mesothelioma Payment Scheme (DMPS)
- Diffuse Mesothelioma Payments – this is called the 2008 scheme
- Pneumoconiosis etc. (Workers' Compensation) Act 1979 (PWCA) – this is called the 1979 Act scheme.

You should always get advice from a specialist solicitor about making a claim for a lump sum payment. You will need to give information about where and how you were exposed to asbestos. The solicitor can help you investigate how you may have been exposed.

It is very important that the information on the benefit application form is filled in correctly. Incorrect information may affect your claim for a lump sum payment, or other compensation claims.

There are time limits for making a claim under some of these schemes:

- Under the PWCA scheme, you must make a claim within 12 months from the award of IIDB.
- Under the DMPS scheme, you must make a claim within 12 months from diagnosis.

If you want to make a claim, you should speak to a specialist solicitor straight away so they can advise you.

Diffuse Mesothelioma Payment Scheme (DMPS)

This scheme provides payments for people who were diagnosed with mesothelioma on or after 25 July 2012. The scheme is only used when someone with mesothelioma has not been able to claim compensation. This may be because:

- their employer is no longer trading
- there is no insurance policy in place to cover the claim.

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

This scheme is only for people who were exposed to asbestos at work and have a strong legal claim against their employer.

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 1 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 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 insurer.

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

Help for people who were in the armed forces

If you were in the armed forces and you have mesothelioma because you came into contact with asbestos, you may be able to make a claim. The claim would be made with your local Veterans Advisory and Pensions Committee. Veterans UK has more information. Call the Veterans UK helpline on **0808 191 4218**.

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 May 1987
- before 15 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 may be a spouse who was exposed to asbestos after handling work clothes contaminated with asbestos. Or you may have regularly visited an area containing asbestos and you were exposed to asbestos dust.

Compensation claims require specialist legal knowledge and must be made through an experienced, specialist solicitor.

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 (DMPS.

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 or illness 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 they died.

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.

Costs of claiming compensation in England and Wales

If you are making a personal injury compensation claim in England and Wales, a specialist solicitor should offer a free first consultation. They should offer to deal with your claim on a 'no win, no fee' basis. They can also 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 professional association
- have legal expenses insurance cover (although these often do not cover these types of claims).

Your solicitor 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, or another responsible organisation. 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 defendant.

Most specialist solicitors offer insurance that covers the cost of the premiums if the claim is unsuccessful. This means in that situation, there is no charge for the premium.

Costs of claiming compensation in 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. You may have to contribute towards legal aid. How much you pay depends on your financial situation.

In Scotland, your solicitor may take your case on a 'no win, no fee basis'. They will arrange insurance to protect you from having to pay any of the defendant's costs or any other expenses.

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 that occurred because of the illness.

This may not be possible if the person who died from mesothelioma had already made a claim that had been settled.

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

Finding a specialist solicitor

When choosing a solicitor, it is important to make sure 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 for more information.

There are many ways you can find a specialist solicitor:

- Ask your specialist nurse or doctor if they have a list of specialist solicitors.
- The Association of Personal Injury Lawyers (APIL) has a list of accredited specialist lawyers.
- 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.

Questions to ask a solicitor

We have suggested some important questions you could ask a solicitor, to make sure they are suitable for your situation:

- Is the solicitor a Fellow of the Association of Personal Injury Lawyers (APIL)?
- Does the solicitor specialise in mesothelioma and asbestos-related disease cases?
- How many asbestos cases has the solicitor handled in the past 3 years?
- How many of these have been dealt with at a court hearing?
- Will the solicitor provide you with a free first consultation? Will they visit you at home, if necessary?
- Will the solicitor provide you with a free summary of what will be involved in making your claim?
- Will they work on a 'no win, no fee' basis?
- Will the solicitor obtain an insurance policy to cover legal fees?
- Will the solicitor take a percentage of your compensation?
- Will you be expected to pay expenses, such as medical report costs and court fees, in advance? How will you be kept informed of what is happening with your claim?
- How long will the claims process take?
- How soon does the solicitor expect to start a court action?

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 have more information that may be helpful:

- Work and cancer – this is also available as an audiobook
- Working while caring for someone with cancer – this is also available as an audiobook
- Self-employment and cancer.

There is also lots more information online at 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.

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.

Information for carers

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Taking care of yourself

If you are a family member or friend of someone who has mesothelioma, you may be a carer. 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.

Caring for someone you love can be emotionally and physically difficult. If you have been looking after them for some time, you may start to feel tired. It can help to talk about how you are feeling. You could talk to a friend or other family member.

There are also many health and social care professionals who can support you and the person you are caring for. You can speak to your GP, or the specialist nurse involved in your friend or relative's care. They can help make sure you are both getting the support you need.

It is important to take a break sometimes. This means letting someone else care for the person you look after for a while. This is called respite care. We have more information online. Visit macmillan.org.uk/respite-care

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 to 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 help you cope. You could also spend time just sitting with and talking to the person you are caring for. This can be very rewarding.

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 avoid talking about it. 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 and like they cannot talk about it either.

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

You may find our booklets helpful:

- Talking with someone who has cancer– this is also available as an audiobook
- Looking after someone with cancer – this is also available as an audiobook

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

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. You can speak to one of our money advisers on 0808 808 00 00.

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.

We also have more information in our booklet Help with the cost of cancer and on our website at macmillan.org.uk/carers-allowance

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 (or procurator fiscal in Scotland). The coroner will carry out an inquest. This is a legal investigation into the circumstances surrounding a person's death.

The coroner is a doctor or lawyer who investigates unexpected or unnatural deaths. Most deaths from mesothelioma are not natural because they are usually caused by exposure to asbestos.

The coroner's investigations should not normally cause a long delay before a funeral can take place. The coroner will issue a temporary death certificate to allow the funeral to go ahead.

The coroner will decide if a post-mortem is needed – this is an examination of the body. In many cases, there is enough medical evidence to confirm the person had mesothelioma. This evidence may come from a biopsy taken when they were diagnosed.

If there is not enough evidence, the coroner may decide a post-mortem is needed. This can confirm if death was caused by mesothelioma or by something else.

Once the coroner has completed their investigations, the inquest can go ahead. This can take several months. You do not have to go to the inquest if you do not want to. The coroner will give a cause of death and issue a final death certificate.

If your family member or friend was making (or had already made) a compensation claim, the coroner should be told and given the solicitor's details. The solicitor should also be told about the death soon after the person dies.

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, so 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. This may include counselling and mental health support as well as bereavement support. You can also call our Support Line.

Mesothelioma UK also has more information about a coroner's inquest in its leaflet **Mesothelioma and the coroner's role**. You can download it from mesothelioma.uk.com

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.

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.

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **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 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

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

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo

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 specialist nurses about things like diagnosis and treatments
- 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 find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

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.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

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. Please note the opening times may vary by service.

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 on0808 808 00 00. Visit macmillan.org.uk/benefits for more information about benefits.

Help with work and cancer

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

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 bring people together in their communities and online.

Support groups

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

Online Community

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

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

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.

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 **0808 278 2515**
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**
www.apil.org.uk
Helps find lawyers for people who are seeking compensation for injury or work-related illnesses.

Asthma + Lung UK

Helpline **0300 222 5800**
www.asthmaandlung.org.uk
Supports people affected by any type of lung disease.

June Hancock Mesothelioma Research Fund

Tel **0114 274 4420**
www.junehancockfund.org
Raises funds for research into mesothelioma. Supports people with mesothelioma and their carers

Mesothelioma UK

Helpline **0800 169 2409**
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 191 4218**
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

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

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

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
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.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the therapist directory page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Anxiety UK

Tel **0344 477 5774**
www.anxietyuk.org.uk
Provides help, information and support for people with anxiety, stress and anxiety-based depression.

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

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**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Citizens Advice

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

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Department for Work and Pensions (DWP)

www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines. Check the website for a list of contact numbers.

GOV.UK

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

GOV.UK Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK Civil Legal Advice

Helpline **0345 345 4345**
Textphone **0345 609 6677**
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

Law Centres Network

www.lawcentres.org.uk
Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 123 3233**

Money Advice Scotland

www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NI Direct

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

NI Direct Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
www.nidirect.gov.uk/contacts/disability-and-carers-service
The service for Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

NI Direct Jobs and Benefits Office

Helpline **0800 022 4250**
Textphone **0800 587 1297**
www.nidirect.gov.uk/contacts/jobs-and-benefits-offices
The office that provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 1111**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for Disabled students.

Living Made Easy

www.livingmadeeasy.org.uk
Provides free, impartial advice and information about all types of disability equipment and mobility products.

Motability Scheme

Tel **0300 456 4566**
www.motability.co.uk
The scheme enables Disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

Scope

Helpline **0808 800 3333**
Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**
www.scope.org.uk
Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for Disabled people.

Support for older people

Age UK

Helpline **0800 678 1602**
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.

Support for LGBTQ+ people

LGBT Foundation

Tel **0345 330 3030**
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.

OUTpatients

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
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 **0808 808 7777**
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.

Advanced cancer and end of life care

Compassion in Dying

Helpline **0800 999 2434**
www.compassionindying.org.uk
Charity providing support for making informed choices and starting honest conversations about death and dying. Provides guides on setting up a will, power of attorney and advance statement.

Hospice UK

Tel **0207 520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309**
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.

The Natural Death Centre

Helpline **0196 271 2690**
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Bereavement support

Cruse Bereavement Care

Helpline **0808 808 1677**
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 is 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 a cancer registry in each country in the UK. They are run by the following organisations.

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

publichealthscotland.scot/population-health/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Disclaimer

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

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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**

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**

Kusamura S, Kepenekian V, Villeneuve L, Lurvink RJ, Govaerts K, De Hingh IHJT, Moran BJ, Van der Speeten K, Deraco M, Glehen O; PSOGI. Peritoneal mesothelioma: PSOGI/EURACAN clinical practice guidelines for diagnosis, treatment and follow-up. Eur J Surg Oncol. 2021;47(1); 6–59. [accessed April 2024].

Popat S, Baas P, Faivre-Finn C, Girard N, Nicholson A, Nowak A, et al. 2021. ESMO Pleural mesothelioma guidelines. Malignant pleural mesothelioma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Available from: www.annalsofoncology.org/action/showPdf?pii=S0923-7534%2821%2904820-1 [accessed April 2024].

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, money 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

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.
2. **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.
3. **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?
4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.
5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

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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 / /

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I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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

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

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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

MACMILLAN
CANCER SUPPORT

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 about treatments for both pleural and peritoneal mesothelioma. There is also information about managing symptoms and what support is available.

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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