



Mesothelioma

This information is for people who have been diagnosed with mesothelioma, their friends, families and carers, and for people who want to know more about the condition.

It explains what mesothelioma is, what causes it and what the symptoms are. It provides information on diagnosis and treatment, and what to expect if you're referred to a hospital cancer clinic. You can also find information on financial help and emotional support.

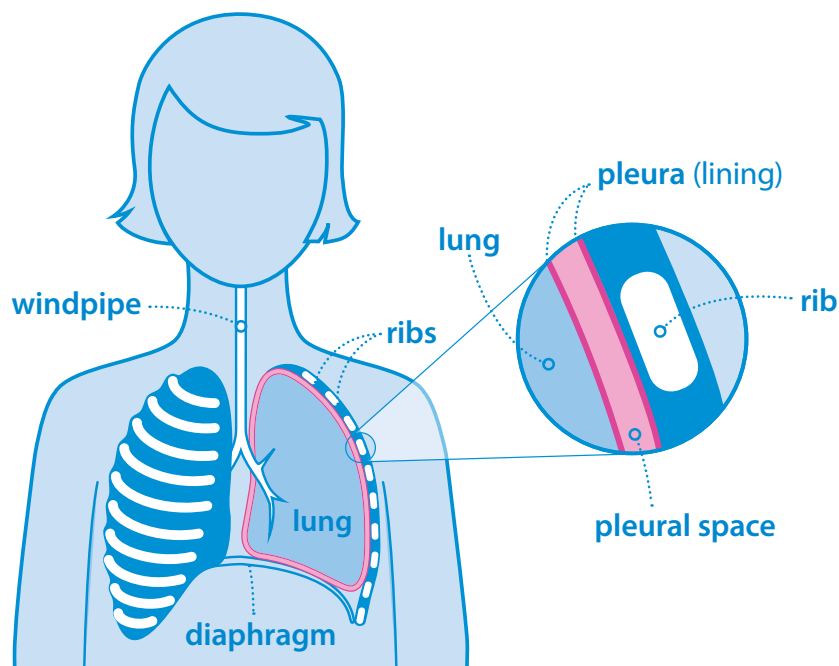
This is how you say mesothelioma: 'mee-zoh-thee-lee-oh-mah'

What is mesothelioma?

Mesothelioma is a type of cancer that begins to grow in the lining of certain organs. Most commonly it affects the lining of the lungs (called the pleura). But it can also affect the lining of the abdomen or the lining of the heart. This information focuses on mesothelioma of the chest, sometimes called **malignant pleural mesothelioma**.

Inside your chest are two thin layers of cells – called the **pleura** or **pleural membranes**. Each layer is about as thin as the skin of a balloon. The inner layer covers your lungs and the outer layer lines the inside of your rib cage.

The space between the two layers is called the **pleural space** and it normally contains a small amount of fluid. This fluid lubricates the two surfaces and lets your lungs and chest wall move and expand as you breathe in and out.



Usually mesothelioma affects only one side of your chest. As the cancer cells grow and multiply, they form lots of small clumps, called tumours. These tumours are scattered throughout the lining of your lung and rib cage causing it to become thicker.

What are the different types of mesothelioma?

There are three different types of mesothelioma of the chest:

- **Epithelioid mesothelioma** is the most common type and accounts for around 75% of cases. This type of mesothelioma grows more slowly than others.
- **Sarcomatoid mesothelioma** is less common. It tends to progress more quickly and has a poorer outcome from treatment.
- **Biphasic mesothelioma** is also uncommon. Biphasic tumours have some parts which are epithelioid and some parts which are sarcomatoid.

Who's at risk of mesothelioma?

The main cause of mesothelioma is breathing in asbestos dust. Asbestos is a naturally occurring fibre that was widely used in construction and other industries until the late 1990s. It was used to insulate and fireproof buildings and was commonly used in ceiling tiles, pipe insulation, boilers and spray coatings used on ceilings and walls.

Asbestos fibres are extremely small. When you breathe them in, they get lodged inside your lungs. These fibres cause persistent irritation to the lungs, which in some people can lead to mesothelioma. It's not known why some people with asbestos in their lungs develop mesothelioma and others don't.

The use of products containing asbestos was banned in the UK in 1999. But it is still found today in many buildings, including homes, public buildings and hospitals. There are now strict guidelines about removing asbestos safely.

Mesothelioma takes a long time to develop. It's normal for people to get the first symptoms 30 to 40 years after they were first exposed to asbestos. So people who have symptoms now might have been exposed many years ago.

People who worked in industries which used asbestos are at higher risk of developing mesothelioma. This includes ship-building, construction and insulation work, but asbestos exposure could have occurred in other jobs.

You can also develop mesothelioma if you lived with someone who worked with asbestos. They may have carried asbestos fibres home on their clothing, where family members could breathe them in. Some people who develop mesothelioma can't remember coming into contact with asbestos and might not have been aware they were exposed to it.

Older people have a higher risk of mesothelioma than younger people. This is because they're more likely to have come into contact with asbestos before the dangers were known. It's also because it takes many years for mesothelioma to develop.

What are the symptoms of mesothelioma?

The symptoms of mesothelioma usually show up 30 to 40 years after a person came into contact with asbestos. The condition is slow to appear and then quick to progress. The main symptoms are:

- feeling out of breath
- coughing
- chest pain.

As mesothelioma develops, it often causes fluid to build up in your pleural space. This is called a **pleural effusion**. This build-up of fluid squashes the affected lung, so it can't expand fully as you breathe. This can make you feel out of breath. Tumours growing around a lung can also stop it expanding properly.

Mesothelioma usually starts in the lining of your chest wall and ribs. If the tumour grows into your chest wall, it can cause pain. It sometimes spreads outside your chest to other organs of your body. But it's unusual for this spread to cause symptoms.

You might experience other symptoms such as fatigue (feeling tired), hot flushes or sweats, loss of appetite and weight loss.

Symptoms tend to develop gradually over weeks or months.

I have symptoms – what should I do?

If you have any of these symptoms, you should ask your GP for a chest X-ray. Remember that in many cases these symptoms could be caused by something other than cancer. They're common symptoms, particularly if you have another long-term lung condition. But it's very important to tell your doctor if your usual symptoms change or become worse.

How is mesothelioma diagnosed?

If your doctor thinks you might have mesothelioma, the first step is usually a chest X-ray. You should have the X-ray within two weeks, and after that you should receive your results within five working days.

If you have mesothelioma, a chest X-ray will often show a pleural effusion (a build-up of fluid) on one side of your chest. There are many possible causes of pleural effusion. If there's no clear explanation, your doctor should refer you to a lung specialist for further tests to find out the cause.

In some cases of mesothelioma, the chest X-ray looks normal. In this case, you would need further tests to confirm whether you have mesothelioma. If you have symptoms and think you have been exposed to asbestos, you should ask your GP for a referral to a lung specialist.

Rapid access clinic

If your chest X-ray shows signs that you might have mesothelioma, you'll be referred to a special clinic at the hospital called the rapid access clinic or urgent cancer clinic. These services are set up to confirm if you have mesothelioma or not, and provide specialist advice and treatment.

Your first appointment with the specialist lung doctor

You may want to bring a partner or friend with you to this appointment – it's good to have moral support and they can help you remember what the doctor says. If you live in England, your first appointment with a specialist should be within two weeks of your GP referral.

At your first appointment, you'll usually see a specialist lung doctor. They'll examine you and ask about your symptoms and medical history. You can help by bringing a list of any medicines you're taking. They may also ask about your job history (and your partner's) to try and find out if you might have been exposed to asbestos.

The doctor will explain the results of any tests you've had so far. You may have already had a CT scan – most clinics offer this before your first specialist appointment. If you've not already had a CT scan, they'll organise one for you and will tell you about any other tests you might need.

Usually, you'll be offered the opportunity to meet a specialist cancer nurse. This nurse is there to help arrange your tests and provide you with further information. They'll give you their contact details so you can get in touch if you have any questions or worries.

The multidisciplinary team

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

Since mesothelioma is not as common as other cancers, multidisciplinary teams might not have a lot of experience in diagnosing and treating it. Some hospitals have come together to develop regional mesothelioma specialist multidisciplinary teams. There's some evidence that these specialist teams offer a wider range of treatment options and access to clinical trials. You should ask if there's a mesothelioma specialist multidisciplinary team in your area that can be involved in your care.

You should be offered follow-up appointments every three to four months with an oncologist, respiratory physician or specialist nurse, depending on your treatment plan. If you wish to be seen less frequently, you should be offered the option of regular telephone follow-up in between face to face visits.

Further tests

It can be difficult to diagnose mesothelioma. As well as a chest X-ray, you'll probably need to have a few different tests. These tests will help to answer the following questions:

- **What is it?** Is it definitely mesothelioma and if so, what type is it?
- **Where is it?** Is the tumour only in your chest or has it spread? This is known as the stage.
- **What do we do about it?** What are your treatment options?

The tests may include a CT scan, MRI scan, PET scan and biopsy as well as blood samples and breathing tests.

CT scan

After a chest X-ray, a **CT scan** (www.nhs.uk/conditions/ct-scan) is the next key step to diagnose mesothelioma. A CT scan is done using a special X-ray machine which produces a detailed image of your chest and of the other organs that the cancer can spread to.

Before the scan, you'll be given an injection in your hand. The injection contains a dye called iodine, so you will be asked if you are allergic to iodine. You'll then be passed through a doughnut-shaped scanner while lying on a flat bed. The scan only takes a few minutes and you won't be inside a tunnel so you shouldn't feel claustrophobic.

The CT scan gives your doctor more reliable information about whether you have mesothelioma and how advanced it is. But it's not always conclusive. Usually you'll need further tests involving a biopsy to confirm if the cause is mesothelioma.

MRI scan

You may also be offered an **MRI scan** (www.nhs.uk/conditions/mri-scan). This scan uses strong magnetic fields and radio waves to produce detailed images of the inside of your body.

PET scan

Some people may be asked to have a **PET scan** (blf.org.uk/support-for-you/breathing-tests/imaging-scans#pet-scan). This is like a CT scan, but with a different sort of dye injected into your hand.

Biopsy

To confirm you have mesothelioma, and which type you have, your doctor will probably need to take a sample of fluid or tissue for testing. This is called a biopsy. There are a few different types of biopsy, but the most common techniques are a pleural aspiration, thoracoscopy, or percutaneous biopsy.

- **Pleural aspiration or tap.** The doctor inserts a thin needle through your skin and into the pleural space around your lungs. They'll usually use an **ultrasound scan** (www.nhs.uk/conditions/ultrasound-scan) to identify the best area to insert the needle. They'll then take a sample of the fluid. This sample goes to the laboratory for testing. Sometimes your doctor might drain a lot of the fluid to relieve symptoms if it's making you feel very out of breath. It's normally carried out with a local anaesthetic, but it's not a very painful procedure so is sometimes done without anaesthetic.
- **Thoracoscopy.** This test is often used if you have a pleural effusion (fluid buildup in the pleural space). The doctor uses a flexible camera called a thoracoscope to look into the pleural space around your lungs. A small cut, about 2cms long, is made in your chest to insert the thoracoscope. Doctors can remove fluid at the same time as taking the biopsy sample. At the same time, sterile talcum powder might be puffed into the chest to try to prevent fluid from building up again in the future. The test is carried out using a local anaesthetic to numb the area and you'll be sedated to make you feel relaxed. Occasionally it has to be done under general anaesthetic. The procedure is usually done as a day case. But, if you have talcum powder put into your chest you will need to be admitted to hospital and stay in for one or two nights.
- **Percutaneous biopsy.** This means taking a sample of tissue from the lining of your lung by passing a thin needle through the wall of your chest. The doctor will use an ultrasound or a CT scan to see the best way in for the needle. They will numb the area with local anaesthetic before taking the biopsy.

The biopsy sample is sent to the laboratory to be examined under a microscope. The results should be available after five to seven days. Sometimes the reading of the biopsy isn't clear. In this case it might be sent away for a second opinion, which means it will take longer.

What stage is your mesothelioma cancer at?

There are three factors used to work out how far your mesothelioma cancer has developed. This is called finding out what stage the cancer is at:

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

Once the doctor knows these results, an overall stage will be decided, showing how large the cancer is and whether it has spread around the body. Generally, mesothelioma is divided into four stages. Stage 1 is the earliest stage and stage 4 is the most advanced stage.

You can read more about the stages of mesothelioma on the **Cancer Research UK website** (www.cancerresearchuk.org/about-cancer/mesothelioma/stages).

Getting my results

Once mesothelioma is confirmed and the stage has been decided, you'll see your specialist doctor to discuss your test results and treatment options. You'll probably want to ask lots of questions, such as:

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

No-one will have all the answers, but the specialist doctor will answer your questions as fully as possible. Your specialist nurse can give you additional support and extra information. If you have more questions, or just need to talk, you can call our helpline on **03000 030 555**

How is mesothelioma treated?

If you live in England, your hospital should aim to start your treatment within one month of diagnosis. If you live in the rest of the UK, treatment should start within one month of your decision to treat. This should be within two months of your original urgent referral.

In some cases, it can take longer to diagnose or treat your condition. Waiting for test results can be frustrating and upsetting. Remember that it's important to get the right treatment, as well as getting it quickly.

What is the outlook for mesothelioma?

Although there have been advances in the treatment of mesothelioma, the outlook for mesothelioma tends to be poor. Treatments are usually aimed at easing your symptoms and improving your quality of life, as well as trying to prolong your life. Your specialist doctor or nurse can talk to you about your outlook in more detail, but it's not always possible to be totally accurate.

Everyone is different and a person's individual outlook will depend on their age, other medical problems and the stage of their tumour. Sadly, because mesothelioma is often diagnosed at an advanced stage, only about 5%-10% of people live for five years or more after diagnosis. However, there is a small group of people who have tumours that are particularly slow growing. These people can live for longer, often up to 10 years or more.

We set up a mesothelioma research network (MRN) to bring together researchers working on mesothelioma. The MRN helps researchers share ideas and support each other, to get better results faster. Find out more about our research into mesothelioma at blf.org.uk/research/our-impact/our-mesothelioma-research

Choosing the best treatment

Once you've been diagnosed with mesothelioma, the members of your care team will study your case to consider what treatment to recommend. The choices will depend on your symptoms, age and general health.

Unlike some types of cancer, there's not a clear medical agreement about treatment for mesothelioma. You'll be offered the treatment that seems best for you. With any treatment, you have to balance the risks and side effects with the possible benefits. You might want to talk to your family or your specialist cancer nurse before making a decision. Your doctor and nurse will be able to discuss the options in detail with you and will respect your views at every step. Find out more about the support that's available to you at blf.org.uk/mesothelioma-support.

The four main types of treatment for mesothelioma are:

- chemotherapy
- surgery
- radiotherapy
- palliative care.

You may also be offered treatment for pleural effusion.

Clinical trials

There's still a lack of evidence about the best treatments for mesothelioma. You might be invited to take part in a medical study, also called a clinical trial, to investigate new treatments.

As well as trials looking into the role of surgery in mesothelioma, there are a large number of clinical trials looking into new drug treatments. This includes assessing the role of **immunotherapy** (www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/immunotherapy) that has been very successful in other cancers.

It's not an option for everyone, but **if you want to know more ask your doctor or nurse**. If you decide not to join a clinical trial, you will still receive the best possible care. You can also leave a clinical trial at any time if you change your mind.

You might also be asked to donate a sample of your tumour to help future research into mesothelioma. This is a choice – you don't have to say yes. You might wish to discuss this with your family and your health care team before you decide.

Cancer Research UK has a database of clinical trials you can search for online: www.cancerresearchuk.org/about-cancer/find-a-clinical-trial

Chemotherapy

Chemotherapy means using powerful medications to destroy cancer cells. If you have chemotherapy, the medications go straight into your blood stream to attack the cancer cells wherever they are. There's evidence that the most effective chemotherapy drug is **pemetrexed**, also called **Alimta**, in combination with a second drug, either cisplatin or carboplatin. You can read more about chemotherapy for mesothelioma on the **Cancer Research UK website** (www.cancerresearchuk.org/about-cancer/mesothelioma/treatment/chemotherapy/pleural).

However, chemotherapy also affects normal cells. This means short-term side effects are common. These might include tiredness, feeling sick (nausea), anaemia (when your body doesn't produce enough red blood cells) and hair thinning. You might also have an increased risk of infection. Your specialist doctor will try to reduce these side effects as much as possible. You may have chemotherapy medications through a drip (a device that slowly puts fluid into your vein), or as injections or tablets. You usually have two courses or cycles of chemotherapy, and then have another CT scan to see how you're responding to the treatment. If the chemotherapy is working, you might be given a course every three weeks, with four to six courses in total.

Surgery

There's a lot of medical debate about surgery to treat mesothelioma. Different approaches are taken in different countries around the world. An operation to remove the whole lung and pleural membrane is called an extra-pleural pneumonectomy. A study looking into this form of surgery found that surgery offers limited benefits and potentially causes harm. Because of this, this surgery isn't offered in the UK anymore. A less extensive operation to remove as much tumour as possible, but to leave your lung behind is called an extended **pleurectomy and decortication**. Doctors are still trying to find out whether this procedure is beneficial. This surgery isn't a standard treatment in the UK, but it is being investigated in clinical trials:

www.cancerresearchuk.org/about-cancer/find-a-clinical-trial/a-trial-looking-at-surgery-for-mesothelioma-mars-2

Radiotherapy

Radiotherapy uses high-energy X-rays to destroy cancer cells. It's usually done with the person lying down in a special scanner and is painless. At the moment, radiotherapy is mainly used to help treat symptoms. For example, it might be given to a painful area to try to reduce the pain. Radiotherapy can cause side effects. Many of these can be treated or prevented, and most will pass after the treatment stops. Side effects of radiotherapy include:

- sore skin
- tiredness
- hair loss (in the area being treated)
- feeling sick (nausea).

You can read more about radiotherapy on the **NHS website** (www.nhs.uk/conditions/radiotherapy) and on the **Macmillan Cancer Support website** (www.macmillan.org.uk/cancer-information-and-support/treatment/types-of-treatment/radiotherapy).

Palliative care

Controlling your mesothelioma symptoms is very important to help maintain or improve your quality of life. You might decide with your doctors that you want to have palliative treatment. Palliative treatment uses medicines or other treatments to control the symptoms you might be getting. Such as a cough, feeling out of breath, pain, loss of appetite or feeling weak. The aim of palliative care is to make you feel as well as possible to improve your quality of life. Palliative care is considered a supportive treatment, and so it can be given alongside surgery, chemotherapy and radiotherapy. It can be beneficial at all stages of mesothelioma to improve your quality of life, not just in the final stages.

Treating pleural effusion

It's common in mesothelioma to get a build-up of fluid in your chest called pleural effusion. It can make people feel breathless, so doctors aim to remove the fluid and prevent it from coming back. There are different ways of treating pleural effusions, which are all as good as each other in terms of improving breathlessness. Each treatment has its own benefits and downsides and different methods will suit different people. Your doctor will discuss the options with you and together you can decide which treatment works best for you. The different treatments are described below, but you can read more about pleural effusion treatments and start thinking about which one might suit you on the My Pleural Effusion Journey website: mypleuraleffusionjourney.com

Repeated pleural taps

Doctors can remove the fluid from your chest using a thin needle. They can repeat this procedure as many times as necessary. However, because the fluid almost always comes back, it's not ideal for you to have to keep having this done. Additionally, in some people the taps become less and less helpful the more they have. Generally, doctors will only choose for you to have repeated pleural taps if:

- you have a very small effusion, or
- you have an effusion that does not make you particularly breathless, or
- your effusion takes a very long time to build up between taps.

Pleurodesis

Your doctors might try to stop the fluid building up with a procedure called pleurodesis. This involves draining off the fluid that's there and then injecting sterile talcum powder into the pleural space between the two layers of your chest lining. This causes the two layers to stick together so there's nowhere for fluid to build up again.

A pleurodesis can be performed in different ways. Sometimes a thin plastic tube called a chest drain is inserted into the pleural space around your lungs to allow the fluid to drain away. Before the drain is inserted, your skin is numbed with local anaesthetic. Once the fluid has been removed, talcum powder is put down the drain into the pleural space. A day or two later the drain is removed. The other way to perform a pleurodesis is to put talcum powder in during a thoracoscopy procedure.

Indwelling pleural catheter

This is when a thin tube (called a catheter) is inserted into your chest and tunnelled under the skin in your armpit. It's left in place so fluid can be drained off as and when needed. The catheter is put in as a day case procedure, under local anaesthetic. Once it is in, you can go home with the catheter hidden under a dressing. The catheter then gets drained at home, either by district nurses or by a member of your family if they wish to be trained how to do it. This avoids the need for you to come into hospital for repeated drainages or for pleurodesis. In some hospitals, doctors can squirt talcum powder down the catheter as an outpatient pleurodesis procedure that avoids you needing to come into hospital.

Taking care of your feelings and available support

Being diagnosed with mesothelioma can be frightening and it's normal to feel overwhelmed. You might feel shock, fear, disbelief, anger, loneliness or resentment. You might feel a mix of these emotions. Sometimes it can be hard to accept that you have cancer and you might feel like you just want to be left alone.

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

When you're ready, it's important to talk about your feelings. You may find it helpful to talk to friends and family. You can also talk with your cancer nurse specialist. If you need more support, your cancer nurse specialist can help you find a counsellor or psychologist. Some GP practices have a counsellor as part of their team.

Support and other organisations that can help

General advice and support

BLF Helpline

Our helpline team of respiratory nurse specialists are there to answer your questions. They can also help you find a local mesothelioma or asbestos support group. Call them on **03000 030 555**. Lines are open 9am to 5pm, Monday to Friday.

Mesothelioma UK

Mesothelioma UK has a helpline, information about mesothelioma and can help you find a support group or specialist solicitor. Mesothelioma UK have also launched a project aiming to provide support for armed forces and veterans affected by mesothelioma.

www.mesothelioma.uk.com

Helpline: 0800 169 2409

Asbestos Awareness and Support Cymru

AASC gives support to people with asbestos-related disease in Wales. It has a network of support groups and works to raise awareness.

www.a-a-s-c.org.uk

Helpline: 01495 272479

Asbestos Victims Support Groups Forum UK

The forum represents asbestos victims support groups and provides advice on benefits and compensation for those with mesothelioma and their families.

www.asbestosforum.org.uk

Action on Asbestos

Action on Asbestos campaigns for people with asbestos-related disease in Scotland. It advises on welfare rights and has a network of support groups. They can also help you find a specialist solicitor in Scotland.

www.clydesideactiononasbestos.org.uk

0141 552 8852 or freephone 0800 089 1717

Mick Knighton Mesothelioma Research Fund (MKMRF)

The MKMRF is now part of the BLF. It aims to raise awareness and fund crucial research projects into mesothelioma.

www.blf.org.uk/mkmrf

Support for carers

Support is available for carers as well. Take a look at these organisations:

Carers Direct

Carers Direct is the NHS resource for carers. It has an online guide to care and support and a helpline.

www.nhs.uk/carersdirect

0300 123 1053

England

Carers Trust

www.carers.org

Carers UK

www.carersuk.org

0808 808 7777

Wales

Carers Trust

www.carers.org/country/carers-trust-wales-cymru

Carers Wales

www.carersuk.org/wales

0808 808 7777

Scotland

Care Information Scotland

www.careinfoscotland.co.uk

0800 011 3200

Carers Trust

www.carers.org/country/carers-trust-scotland

Carers Scotland

www.carersuk.org/scotland

0808 808 7777

Northern Ireland

Carers Trust

www.carers.org/country/carers-trust-northern-ireland

Carers NI

www.carersuk.org/northernireland

028 9043 9843

Financial support

If you have mesothelioma, your financial circumstances might change. You might have extra expenses such as travel costs to hospital. You might feel worried about how you and your family are going to manage financially. If you're diagnosed with mesothelioma, you and your family can apply for financial assistance.

You might be entitled to claim general state benefits. This can really help with your family's income. Some key benefits to be aware of are:

Industrial injuries disablement benefit (IIDB) (www.gov.uk/industrial-injuries-disablement-benefit).

This is for people who can show they were exposed to asbestos in their job (even if they didn't work directly with asbestos). People cannot claim who were self-employed at the time they were exposed to asbestos.

Personal Independence Payment (PIP) (www.gov.uk/pip), previously known as Disability Living Allowance, is available (depending on your circumstances) if you are aged under 65 when you apply.

Attendance Allowance (www.gov.uk/attendance-allowance) is a benefit for people aged 65 or older.

Carer's Allowance (www.gov.uk/carers-allowance) is for people who care for someone with substantial caring needs for 35 hours a week or more.

Employment and Support Allowance (www.gov.uk/employment-support-allowance) is a benefit for people who are of working age but are unable to work because of their illness.

The **Blue Badge scheme** is a parking badge which helps you park closer to your destination. For more information, go to the following websites:

- England and Wales: www.gov.uk/blue-badge-scheme-information-council
- Scotland: www.mygov.scot/apply-blue-badge
- Northern Ireland: www.nidirect.gov.uk/services/apply-or-renew-blue-badge-online

Special rules for terminally ill people. If a person is terminally ill and expected to live for six months or less, they can get Attendance Allowance or Personal Independence Payment immediately. The Department of Work and Pensions (DWP) will fast-track the application

You can read more about these benefits in our welfare benefits information (blf.org.uk/welfare-benefits). You can also read free online advice and find your local Citizen's Advice Bureau (CAB) on the CAB website (www.citizensadvice.org.uk).

Specialist legal support

If you've been diagnosed with mesothelioma it's likely you can claim compensation. In this section we explain the options available to you and the steps you or your family can take.

There are several options. You might decide to:

- Pursue a civil claim against your former employer
- Claim from compensation funds
- Claim various state benefits.

Get expert advice as soon as you can. Claiming compensation is time-limited – usually three years from when you were diagnosed for a civil claim, 12 months for a lump sum compensation claim from government schemes.

Applying for compensation can seem daunting, but there are many people who can offer advice and will help guide you through the process at no cost.

A good way to start is by contacting your local Citizens Advice Bureau or speaking to the welfare benefits office at your local council. You can also find details of UK asbestos support groups online at asbestosforum.org.uk. In Scotland, get in touch with Action on Asbestos at www.clydesideactiononasbestos.org.uk

You can also call our helpline on **03000 030 555**. We can tell you about state benefits and where to find local help with your application. We can also refer you to a local asbestos support group where you can get practical help with claiming compensation from the various government funds.

Pursuing a civil claim

If you were exposed to asbestos while in employment, you might wish to pursue a civil claim against that previous employer. It's important to use a solicitor who is a specialist in mesothelioma claims and make sure that they have a good track record. You can ask them how many cases they've won and ask for client stories, called case studies. Mesothelioma UK has advice about making a claim and questions to ask. The Association of Personal Injury Lawyers lists specialist solicitors. In Scotland, get in touch with Action on Asbestos at www.clydesideactiononasbestos.org.uk

Specialist mesothelioma solicitors

If you choose to take legal action, it's important to work with a solicitor who has specific experience with mesothelioma cases. Not all solicitors, even those who work in personal injury, are specialists in mesothelioma claims.

Association of Personal Injury Lawyers

APIL has a list of accredited specialist solicitors.

www.apil.org.uk/accredited-injury-lawyers/asbestos-disease-specialists

Law Society

The Law Society provides information about organisations and people who provide legal services and are regulated.

England and Wales

www.lawsociety.org.uk/

020 7320 5650

Scotland

www.lawscot.org.uk

0131 226 7411

Northern Ireland

www.lawsoc-ni.org

028 9023 2606

Some specialist solicitors are part of our Mesothelioma patrons scheme. Find out more at blf.org.uk/take-action/lets-work-together/mesothelioma-patrons/legal

Compensation funds

If you have mesothelioma there are different financial options available to you, depending on your circumstances. You can find out about benefits and compensation funds administered by the government on their website at www.gov.uk

Remember time limits apply, so get expert help as soon as you can. In some cases, you can claim if you were a dependent of a person with mesothelioma who has died.

Pneumoconiosis Etc. (Workers' Compensation) Act 1979

www.gov.uk/industrial-injuries-disablement-benefit/further-information

A lump sum available to some people awarded industrial injuries disablement benefit, who apply within 12 months of that award if their employer no longer exists or the work that caused their mesothelioma was over 20 years ago.

Diffuse mesothelioma payments (the '2008 scheme')

www.gov.uk/diffuse-mesothelioma-payment

A lump sum available for people who lived with an asbestos worker or near a factory that used asbestos. This fund also helps people who were exposed to asbestos while self-employed. You must claim this within 12 months of diagnosis.

Diffuse Mesothelioma Payment Scheme (DMPS)

www.mesoscheme.org.uk

You should first check with a solicitor if you can make a claim against your responsible employer or your employer's solicitor. If you can't, you or your solicitor can apply to the DMPS scheme if you were diagnosed with diffuse mesothelioma on or after 25 July 2012 and meet other criteria.

War Pensions Scheme

www.gov.uk/guidance/war-pension-scheme-wps

If you have mesothelioma because you came into contact with asbestos while serving in the armed forces, you might be able to make a claim under the War Pensions Scheme. If you worked for the Ministry of Defence (MOD) as a civilian and came into contact with asbestos, you may be able to claim under the schemes above. There are several payments and schemes available depending on your circumstances. Find out more from Veterans UK. Call **0808 1914 218** or visit their website at www.gov.uk/government/organisations/veterans-uk

Thinking about the end of your life

It's often hard to think about death, but it can make things easier on your loved ones if you make decisions and plan in advance. There are a few things that you should know so you can inform those closest to you.

Making a will

By making a will you can decide what happens to your property and possessions. You can draw up a will yourself, but it's best to get legal help because there are certain rules to follow when writing the document.

Have a look at our **free will writing service** (blf.org.uk/legacies/our-free-will-writing-service) where you can get a basic will written for free by a participating solicitor in your area. You can also contact your local Citizens Advice Bureau for a list of solicitors who can help either by writing the will for you, or checking a will you have written.

Putting your affairs in order

It can be helpful to let your family know where they can find:

- your financial records such as your bank, building society, credit card and pension details
- important documents such as your passport, insurance documents and house deeds
- details of your gas, water and electricity suppliers, as well as anyone you have hire or credit agreements with
- details of your last wishes and any pre-paid funeral plans.

Lasting power of attorney (LPA)

Towards the end of your life you might become unable to make decisions about your financial affairs or welfare.

A lasting power of attorney (LPA) allows you to stay in control by choosing a person to make these decisions for you. You can set one up if you can show you understand and approve of what is involved. Find out more for:

- **England and Wales:** www.gov.uk/power-of-attorney
- **Scotland:** www.publicguardian-scotland.gov.uk/power-of-attorney
- **Northern Ireland:** www.nidirect.gov.uk

Advance statement or advance care plan

An advance statement or care plan is sometimes called a living will. It's a way for you to write down and tell those important to you, including health and social care teams, what is important to you about your care and treatment. It's used to share your wishes and preferences, as well as help make decision on your behalf if you become unable to say so yourself. For more information on advance care planning take a look at the Marie Curie website: www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/advance-care-planning

Involvement of the coroner

Mesothelioma is classed as an industrial disease. This means that, in **England** and **Wales**, all deaths from mesothelioma must be referred to the local coroner's office. The coroner will then decide if a post-mortem examination is required and will hold an inquest. A death certificate can only be issued after the inquest. This can be a very difficult time for family and loved ones and it really helps to be clear about the process surrounding the inquest. The government has a guide you can read through: www.gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide

In **Northern Ireland**, deaths relating to mesothelioma must be reported to the coroner. The coroner will decide whether an inquest needs to be held, but the family can make their views known and these will be considered before any decision is made. A post-mortem may take place if there's a possibility that it would help to learn more about the disease or to obtain tissue samples.

In **Scotland**, a doctor must report a death from mesothelioma to the procurator fiscal (public prosecutor in Scotland), who has a duty to investigate. If mesothelioma has been diagnosed by a biopsy when the person was alive, it may be possible for the cause of death to be certified without a post-mortem. Since 2014, the procurator fiscal and chief medical officer have agreed procedures to reduce distress to the family. This process also aims to establish the facts that may be required for a civil case for compensation. Action on Asbestos has more information: www.clydesideactiononasbestos.org.uk

Compensation

If you haven't already claimed, your family can claim compensation after your death.

Our helpline team is dedicated to answering your questions. Call our helpline on **03000 030 555**. Lines are open 9am to 5pm, Monday to Friday.

Get in touch with us to find support near you.

Helpline: **03000 030 555**

Monday to Friday, 9am-5pm

Ringing our helpline will cost the same as a local call.

helpline@blf.org.uk

blf.org.uk

Code: BK7 **Version:** 5

blf.org.uk/mesothelioma

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Due for medical review: November 2023

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