



# Mesothelioma

## About this information

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.

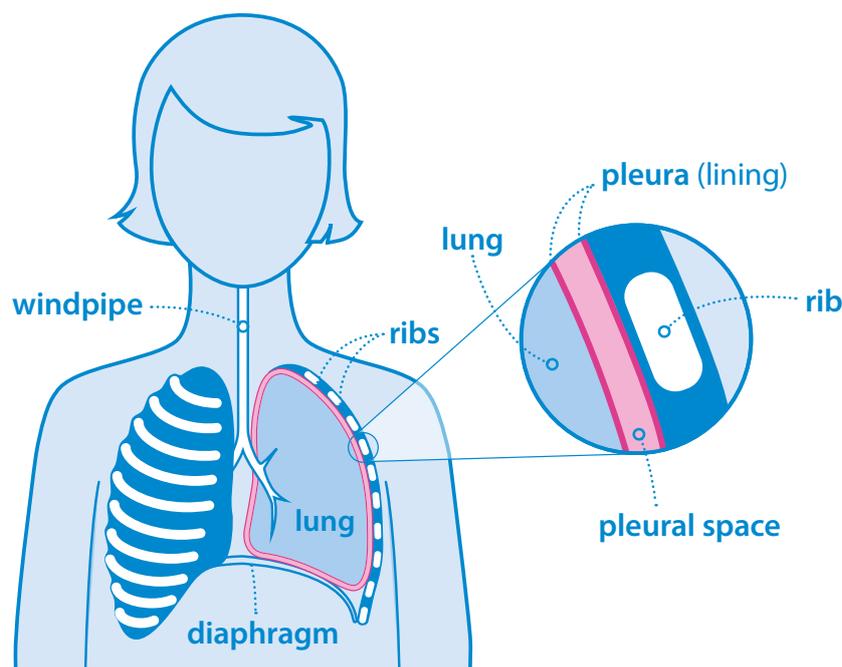
It explains what mesothelioma is, what causes it and what the symptoms are. It provides information on diagnosis and treatment, and what to expect if you're referred to a hospital cancer clinic. You can also find information on financial help and emotional support.

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 pleural membrane. Your chest contains two thin layers of cells – an outer layer that lines the inside of your rib cage and an inner layer that covers your lungs. These layers are called the **pleura** or **pleural membrane**. Each layer is about as thin as the skin of a balloon.

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.



Mesothelioma can affect a similar lining around your abdomen or heart, but this is less common. This information focuses on mesothelioma of the chest, sometimes called **malignant pleural mesothelioma**.

Usually mesothelioma affects only one side of your chest. As the cancer cells grow and multiply, they form clumps called tumours. Sometimes there's just one large tumour. More commonly, there are lots of small tumours scattered throughout your pleural membrane. These cause the pleural membrane to become thicker.

There are three different types of mesothelioma:

- **Epithelioid mesothelioma** is the most common type. This type of mesothelioma grows more slowly than others, so it might respond better to treatments.
- **Sarcomatoid mesothelioma** is less common. It tends to progress more quickly and has a poorer outcome from treatment.
- **Biphasic mesothelioma** is also uncommon. It's more aggressive than epithelioid mesothelioma but grows more slowly than sarcomatoid mesothelioma.

## Who's at risk?

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.

The use of products containing asbestos was banned in the UK in 1999. But it's still found today in many buildings, including homes, schools 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. They include:

- carpenters and joiners
- plumbers, heating and ventilation engineers
- electricians, electrical fitters
- pipe fitters
- metal plate workers, shipwrights, riveters
- labourers in other construction trades
- sheet metal workers
- construction operatives
- energy plant operatives
- painters and decorators
- building inspectors
- vehicle body builders and repairers
- metalworking production and maintenance fitters
- shipbuilding workers
- railway engineering workers
- people who have worked on DIY projects, particularly Artexing ceilings or working with guttering or insulation materials

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 partly because it takes so many years for mesothelioma to develop, but also because they are more likely to have come into contact with asbestos before the dangers were known.

Mesothelioma is much less common in women, probably because they are less likely to have worked directly with asbestos.

## What are the symptoms of mesothelioma?

The symptoms of mesothelioma only 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 plumpers
- 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 your lung, so it can't expand fully as you breathe. This makes you feel out of breath. Tumours growing around your lung can also stop your lung expanding properly.

Mesothelioma usually starts in the outer pleural membrane that lines the inside of your chest wall and ribs. The tumour often causes pain in your chest as it grows into your chest wall. 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), loss of appetite and weight loss.

Symptoms tend to develop gradually over weeks or months. Some patients put up with the symptoms until they're really struggling with breathing, and then have to be admitted to hospital urgently for treatment.

## I have symptoms that I'm worried about – what should I do?

If you have any of these symptoms, you should talk to your GP. 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 for further tests to find out the cause.

In some cases of mesothelioma the 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 for a referral to a hospital cancer clinic if possible.

### 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.

### My first appointment with the specialist

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 to try and find out when 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** (see page 5) – 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 lung cancer and 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, individual multidisciplinary teams might not have a lot of experience in diagnosing and treating it. Some hospitals have come together to develop 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 might want to ask if there's a mesothelioma specialist multidisciplinary team in your area that can be involved in your care.

## 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 this 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 (see page 6).
- **What do we do about it?** What are your treatment options?

The tests may include a **CT scan** and **biopsy** as well as blood samples and breathing tests.

### CT scan

After a chest X-ray, a 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 iodine, so make sure you tell the hospital staff if you're allergic. 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 much more reliable information about whether you have mesothelioma, and how advanced it is. But it's not always conclusive. For example, it might show that you have a pleural effusion, but won't confirm the cause. Usually you'll need further tests to confirm if the cause is mesothelioma.

You may be offered other scans:

**MRI scan:** This scan uses strong magnetic fields and radio waves to produce detailed images of the inside of your body. The MRI scanner is a large tube. You lie inside the tube during the scan.

**PET scan:** For this scan you're injected with a substance called a radiotracer which gives off a small amount of radiation. You then lie on a flat bed which passes through a doughnut-shaped scanner. The scanner detects the radiation, producing a detailed image of the inside of your body.

### Biopsy

To confirm that you have mesothelioma, and which type you have, your doctor might 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 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. You might be offered a local anaesthetic, but it's not a very painful procedure so you don't have to have it.

- **Thoracoscopy.** This is becoming the test that doctors prefer to use for the best results if you have a pleural effusion. The doctor uses an instrument called a thoracoscope to look into the pleural space around your lungs. A small cut is made in your chest to insert the thoracoscope. It also allows the doctor to remove fluid or take a sample of tissue. 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 usually 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. It's likely that you'll be admitted to hospital and will 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 sample is sent to the laboratory for examination under the microscope. The doctor might use ultrasound or CT scan to see the best way in for the needle.

The results of your biopsy should be available after five to seven days. Sometimes the reading of the biopsy isn't straightforward and it might need to be sent away for a second opinion, which means that it will take longer.

### What stage is my cancer at?

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

- **T-stage** – how large is the primary **T**umour (where the cancer started) and what parts of your chest are affected?
- **N-stage** – has the cancer spread to any lymph glands (also called **N**odes)?
- **M-stage** – has the cancer spread (or **M**etastasised) to other areas in your body?

Once the doctor knows these three things, 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.

### Getting my results

Once you've had your tests 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 honestly and 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 treatment within one month of diagnosis. If you live in the rest of the UK, you should start treatment within one month of the 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 tests and results can be frustrating and upsetting. Remember that it's important to get the right treatment as well as getting treatment quickly.

## What should I expect?

Although there have been advances in the treatment of mesothelioma, it's still usually regarded as a terminal condition. Sadly, only around 5% to 10% of people diagnosed with mesothelioma will survive for five years or more. The condition is often diagnosed at an advanced stage, and people with mesothelioma are often elderly and have other health problems.

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.

## 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 it would be best to recommend. The choices will depend on your symptoms and your 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 a doctor you know well before you make 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.

The four main types of treatment for mesothelioma are:

- chemotherapy
- surgery
- radiotherapy
- palliative care

## 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, including outside your lung. There's evidence that the most effective chemotherapy drug is **pemetrexed**, also called Alimta, in combination with a second drug, usually cisplatin, or carboplatin in less fit patients.

However, chemotherapy also affects normal cells, which means short-term side effects are common. These might include nausea, anaemia (when your body doesn't have enough iron) and hair loss. 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 round 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. This surgery isn't offered in the UK.

A less extensive operation to remove as much tumour as possible but to leave your lung behind is called a **radical 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 you may be offered it as part of a clinical trial. At the moment a UK study called MARS-2 is comparing the use of chemotherapy only with the use of chemotherapy plus radical pleurectomy and decortication.

## Radiotherapy

Radiotherapy uses high-energy X-rays to destroy cancer cells. It's usually done with the person lying down 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.

## 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, including assessing the role of 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'll 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 – and you might wish to discuss this with your family and your health care team before you decide.

## Palliative care

Controlling your mesothelioma symptoms is very important and you might decide with your doctors that you want to have palliative treatment. This 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 treatment can be given alongside surgery, chemotherapy or radiotherapy. It can be beneficial at all stages of mesothelioma, not just in the final stages. Your specialist doctor might be able to refer you to a palliative care team who can visit you and your family at home. Some of these teams are linked to a local hospice, and can provide lots of additional help and support during your illness.

## Treating pleural effusion

It's common in mesothelioma to get a build-up of fluid in your chest called pleural effusion. The fluid can be removed on a regular basis, but it can become more and more difficult to make this work. So other options are sometimes used:

### 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 (see page 6).

### Indwelling pleural catheter

If a pleurodesis fails to control the build-up of fluid, a tube can be inserted into your chest through the skin, and left in place so that fluid can be drained off as and when needed. This avoids the need for you to be admitted into hospital repeatedly for procedures to insert tubes.

## Taking care of your feelings

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 some or all 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 that you feel able to talk about your feelings. You may find it helpful to talk to friends and family, and you can also talk with your cancer nurse specialist. If you need more support, your specialist nurse can help you find a counsellor or psychologist. Some GP practices have a counsellor as part of their team.

## 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. There are several options. You might decide to:

- pursue a civil claim against your former employer
- claim from compensation funds
- claim various state benefits

These are 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. So get expert advice as soon as you can. Applying for benefits 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 calling our helpline on **03000 030 555** and asking to speak to one of our welfare benefits advisers. We can tell you about state benefits and where to find local help with your application. We can also refer you on to a local asbestos support group where you can get practical help with claiming compensation from the various government funds.

You could also contact your local Citizens Advice Bureau, or speak to the welfare benefits office at your local council. You can find details of UK asbestos support groups at **[www.asbestosforum.org.uk](http://www.asbestosforum.org.uk)**. In Scotland, get in touch with Clydeside Action on Asbestos (CAA) at **[www.clydesideactiononasbestos.org.uk](http://www.clydesideactiononasbestos.org.uk)**

### 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 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 Clydeside Action on Asbestos (CAA). Contact details for both are on page 14.

Some specialist solicitors are part of our Mesothelioma patrons scheme.

› [www.blf.org.uk/take-action/lets-work-together/mesothelioma-patrons/legal](http://www.blf.org.uk/take-action/lets-work-together/mesothelioma-patrons/legal)

## Compensation funds and state benefits

If you have mesothelioma there are different financial options available to you, depending on your circumstances. You can find out more about benefits and compensation funds administered by the government at [www.gov.uk](http://www.gov.uk). Some of the available benefits and compensation funds are listed below.

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.

**Industrial injuries disablement benefit (IIDB):** For people who can show they were exposed to asbestos (not necessarily worked directly with asbestos) their job. People cannot claim who were self-employed at the time they were exposed to asbestos.

**Pneumoconiosis Etc. (Workers' Compensation) Act 1979:** 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'):** Designed for people who were not exposed at work. For example, people who lived with an asbestos worker or near a factory that used asbestos. This fund also helps people who were self-employed when they were exposed.

**Diffuse Mesothelioma Payment Scheme (DMPS):** 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 find either of them, 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.

➤ For more information go to [mesoscheme.org.uk](http://mesoscheme.org.uk)

**War Pensions Scheme:** If you worked for the MOD as a civilian and came into contact with asbestos, you may be able to claim under the schemes above. 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. There are several payments and schemes available depending on your circumstances.

➤ Find out more from Veterans UK. Call **0808 1914 218** or go to [www.veterans-uk.info](http://www.veterans-uk.info)

You might also be entitled to claim general state benefits to help with your family's income. For example:

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

➤ See [www.gov.uk/pip](http://www.gov.uk/pip) for more information.

**Attendance Allowance** is a benefit for people aged 65 or older.

➤ See [www.gov.uk/attendance-allowance](http://www.gov.uk/attendance-allowance) for more information.

**Carer's Allowance** is for people who are looking after someone who receives a disability benefit. For more information see:

➤ [www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance) (England and Wales)

➤ [www.careinfosctoland.co.uk](http://www.careinfosctoland.co.uk) (Scotland)

➤ [www.nidirect.gov.uk](http://www.nidirect.gov.uk) (Northern Ireland)

**Employment and Support Allowance** is a benefit for people who are of working age but are unable to work because of their illness.

➤ See [www.gov.uk/employment-support-allowance](http://www.gov.uk/employment-support-allowance) for more information.

**The Blue Badge scheme** is a parking badge which helps you park closer to your destination if you're disabled. For more information, contact the welfare benefits advisers at your local council, or visit:

➤ [www.gov.uk/blue-badge-scheme-information-council](http://www.gov.uk/blue-badge-scheme-information-council) (England and Wales)

➤ [www.mygov.scot/apply-blue-badge](http://www.mygov.scot/apply-blue-badge) (Scotland)

➤ [www.nidirect.gov.uk](http://www.nidirect.gov.uk) (Northern Ireland)

## 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 plans in advance. There are a few things that you should know about 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.

You can 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 details 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 life you might become unable to make decisions about your financial affairs or welfare. An LPA allows you to stay in control by choosing a person to make these decisions for you. You can set one up as long as you can show you understand and approve of what is involved. Find out more at:

➤ [www.gov.uk/power-of-attorney](http://www.gov.uk/power-of-attorney) (England and Wales)

➤ [www.publicguardian-scotland.gov.uk/power-of-attorney](http://www.publicguardian-scotland.gov.uk/power-of-attorney) (Scotland)

➤ [www.nidirect.gov.uk](http://www.nidirect.gov.uk) (Northern Ireland)

### Advance statement or advance directive (living will)

An advance statement or directive is sometimes called a living will. This is a way for you to write down and tell those important to you, including health and social care teams, what you know about your illness and what is important to you about your care and treatment. It's used to show what medical treatment you would like to receive if you become unable to make decisions. For example, you can leave instructions about whether you want to be resuscitated if your heart stops or receive artificial ventilation in intensive care. For advice in these matters it's worth talking to a solicitor. Find out more at

[patient.info/doctor/advance-care-planning](http://patient.info/doctor/advance-care-planning) or [ihub.scot/anticipatory-care-planning-toolkit](http://ihub.scot/anticipatory-care-planning-toolkit) (Scotland).

## 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 short guide [www.gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide](http://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, 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. Clydeside Action on Asbestos has more information: [www.clydesideactiononasbestos.org.uk](http://www.clydesideactiononasbestos.org.uk)

## Compensation

If you haven't already claimed, your family can claim compensation after your death. Our helpline can explain the options – call **03000 030 555**.

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.

## Sources of support

### BLF Helpline

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

### Mesothelioma UK

Mesothelioma UK offers a helpline, information about mesothelioma and can help you find a support group or specialist solicitor.

> [www.mesothelioma.uk.com](http://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](http://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](http://www.asbestosforum.org.uk)

## Clydeside Action on Asbestos

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

➤ [www.clydesideactiononasbestos.org.uk](http://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](http://www.blf.org.uk/mkmrf)

## Benefits, money and compensation

### GOV.UK

Read about benefits and compensation on the government's main website:

➤ [www.gov.uk](http://www.gov.uk)

### Citizens Advice

Read free online advice and find your local Citizens Advice at:

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

## Specialist legal support

If you choose to take legal action, it's important to work with a solicitor who has specific experience with mesothelioma cases.

### Association of Personal Injury Lawyers

APIL has a list of accredited specialist solicitors.

➤ [www.apil.org.uk/accredited-injury-lawyers/asbestos-disease-specialists](http://www.apil.org.uk/accredited-injury-lawyers/asbestos-disease-specialists)

Some specialist solicitors are part of our Mesothelioma patrons scheme.

➤ [www.blf.org.uk/take-action/lets-work-together/mesothelioma-patrons/legal](http://www.blf.org.uk/take-action/lets-work-together/mesothelioma-patrons/legal)

### Law Society

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

➤ England and Wales	<a href="http://www.lawsociety.org.uk">www.lawsociety.org.uk</a>	020 7320 5650
➤ Scotland	<a href="http://www.lawscot.org.uk">www.lawscot.org.uk</a>	0131 226 7411
➤ Northern Ireland	<a href="http://www.lawsoc-ni.org">www.lawsoc-ni.org</a>	028 9023 2606

## Carers, family and friends

### England

Carers Trust

➤ [www.carers.org](http://www.carers.org)

Carers UK

➤ [www.carersuk.org](http://www.carersuk.org)      0808 808 7777

## Wales

Carers Trust

➤ [www.carers.org/country/carers-trust-wales-cymru](http://www.carers.org/country/carers-trust-wales-cymru)

Carers Wales

➤ [www.carersuk.org/wales](http://www.carersuk.org/wales) 0808 808 7777

## Scotland

Care Information Scotland

➤ [www.careinfoscotland.co.uk](http://www.careinfoscotland.co.uk) 0800 011 3200

Carers Trust

➤ [www.carers.org/country/carers-trust-scotland](http://www.carers.org/country/carers-trust-scotland)

Carers Scotland

➤ [www.carersuk.org/scotland](http://www.carersuk.org/scotland) 0808 808 7777

## Northern Ireland

Carers Trust

➤ [www.carers.org/country/carers-trust-northern-ireland](http://www.carers.org/country/carers-trust-northern-ireland)

Carers NI

➤ [www.carersuk.org/northernireland](http://www.carersuk.org/northernireland) 028 9043 9843

## 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](http://www.nhs.uk/carersdirect) Helpline: 0300 123 1053

Get in touch with us to find support near you.

Helpline: 03000 030 555

Monday to Friday, 9am-5pm

Ringling our helpline never costs more than a local call and is usually free, even from a mobile.

[helpline@blf.org.uk](mailto:helpline@blf.org.uk)

[blf.org.uk](http://blf.org.uk)

British Lung Foundation  
73-75 Goswell Road  
London EC1V 7ER

Registered charity in England and Wales (326730), Scotland (038415) and the Isle of Man (1177)



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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**