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# PERITONEAL MESOTHELIOMA

INCLUDING SYMPTOMS AND HOW TO MANAGE THEM

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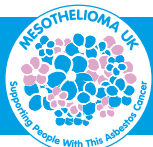
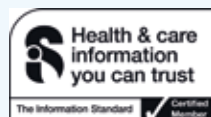
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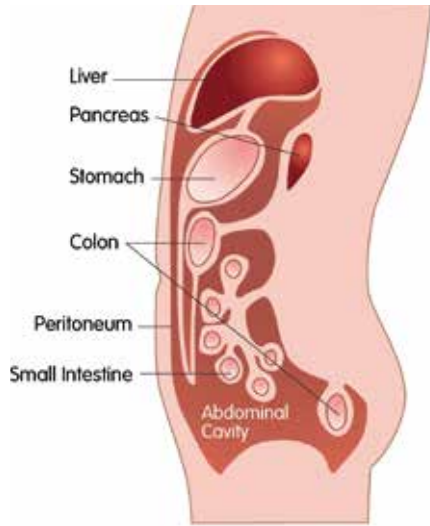
# MESOTHELIOMA UK

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### What is peritoneal mesothelioma?

The peritoneum is the lining of the abdomen. It has two layers: the inner (visceral) layer, which is next to the abdominal organs, and the outer (parietal) layer, which lines the abdominal wall. The peritoneum helps to protect the contents of the abdomen and keep them in place. It also produces fluid that acts as a lubricant and helps the abdominal organs move smoothly against each other.

Mesothelioma in the peritoneum is called **Peritoneal Mesothelioma**.

Like mesothelioma arising in the lining of the ribcage (pleural mesothelioma), peritoneal mesothelioma is caused by exposure to asbestos. It is believed that peritoneal mesotheliomas may arise after longer and heavier periods of asbestos exposure than pleural mesotheliomas.

Peritoneal mesothelioma is very much less common than pleural mesothelioma and though we do not know the precise figures, they probably represent no more than 5-10% of all mesotheliomas.

Peritoneal mesothelioma causes thickening of the membranes surrounding the abdominal organs and often a collection of fluid in the abdomen. The collection of fluid is called ascites and causes swelling of the abdomen. (See separate factsheet).

### How is peritoneal mesothelioma diagnosed?

People who develop malignant peritoneal mesothelioma may often have mild, vague symptoms including abdominal

pain, sometimes with abdominal swelling, constipation or diarrhoea, tiredness, loss of appetite and weight loss. Because the symptoms are non-specific, and because the history of exposure to asbestos may have been many years previously, there is often a delay before the diagnosis of peritoneal mesothelioma is suspected. Occasionally patients will have had symptoms for several months or even years before the diagnosis is confirmed. A CT scan of the abdomen will probably be advised to help with the diagnosis. This can show the thickening of the wall of the abdomen.

An ultra-sound scan may be used to find the best place to put a needle in the abdomen to draw off some fluid. If the diagnosis is still uncertain, it may be necessary to have a further test called a laparoscopy.

A laparoscopy is a surgical procedure that allows the doctor to look inside the abdomen. It is minimally invasive, or keyhole, surgery. The surgeon only has

to make one or two small cuts in the skin.

A small flexible tube that contains a light source and a camera called a laparoscope can be passed through the abdominal wall and the surgeon can look inside and take samples of tissue. These are then sent off to the laboratory to be looked at under a microscope.

### Treatment

The choice of treatment for peritoneal mesothelioma, as with other cancers, depends on a number of factors including general fitness, other illnesses and how advanced the disease is.

Occasionally surgery for early stage peritoneal mesothelioma is performed in a few specialist centres. The aim of the surgery is to remove as much tumour as possible from the abdominal (tummy) wall in order to relieve the symptoms of the disease.

Slightly heated chemotherapy (anti-cancer) drugs, are sometimes put in the abdominal space at the same time as the surgery.

This method of delivery of chemotherapy is quite new and may be offered as part of a clinical trial.

### Chemotherapy (drug treatment)

The National Institute for Health and Clinical Excellence (NICE) has recommended Pemetrexed as a treatment option for people with advanced mesothelioma. Apart from chemotherapy given at the time of surgery as described in the previous section, it is usually given in combination with another drug, Cisplatin, by injection into a vein.

Chemotherapy for mesothelioma will not cure the cancer but it can help to improve the symptoms and for some people, delay the progression of the disease. Like all chemotherapy treatments, there are several potential side effects and it is important to be well enough to tolerate these. Further information about chemotherapy for mesothelioma can be found on another factsheet.

## Symptoms and How to Manage Them

Unfortunately peritoneal mesothelioma is often diagnosed when the disease is quite advanced. It is important therefore to try to help with symptoms. Accumulation of fluid in the abdomen can cause discomfort. If this becomes a problem, a small tube can be passed through the skin into the abdomen and the fluid can be drained off. More recently a small tube has been developed that is designed to stay in place more permanently so that fluid can be drained off at home without the need for repeated hospital visits. Further information about this can be found on another factsheet.

The symptoms of peritoneal mesothelioma can include discomfort or pain, distended abdomen, constipation or diarrhoea, feeling sick (nausea) or being sick, indigestion, loss of appetite and weight loss and night sweats. You may also feel more tired and less inclined to do things,

therefore making you less active and sometimes low in mood.

This leaflet will explain these symptoms, and look at how to try to manage them.

### Pain

**Pain** in peritoneal mesothelioma varies from person to person, and often depends on the causes of the pain. Some words used to describe pain can include “discomfort”, “aching”, “soreness”, “a twinge”, “sharp”, “stabbing”, “tightness” or “bloating”. You may be asked to describe your pain by your doctor or nurse, as this can help them work out the type of pain you are having and suggest the best type of treatment for it.

One of the possible complications of peritoneal mesothelioma is bowel obstruction. This can be caused by the mesothelioma or by ascites (the fluid that accumulates in your abdomen). This can increase the pressure in the abdomen causing bloating and swelling. It can also cause sickness, constipation and make you feel out of breath more easily. It is important to report these

symptoms to your doctor or nurse immediately as you might need to come into hospital to have it treated.

Generally, most types of cancer pain can be reduced, so let your doctor, nurse or pharmacist know if you are in pain. They can assess your pain and suggest ways to help, for example pain killing medication or draining the fluid in the abdomen.

Some complementary therapies, such as relaxation, massage, reflexology or acupuncture can also help with pain. Your local nurse, cancer information centre, hospice or support group may be able to give you more information about this. Further information can be found in the Macmillan booklet “Controlling Cancer Pain”.

### Draining Ascites

Draining ascites can often help relieve pain and discomfort in the abdomen. It can also reduce the risk of bowel obstruction. The fluid is normally drained with the help of an ultrasound scan which can help guide the doctors to where the fluid is located. Draining the fluid can be done in more than one way.

- **Ascitic tap**

This is a small tube which is inserted into the fluid in the abdomen and attached to a bag to allow it to drain out. You usually need to spend a few days in hospital for this procedure. The length of time depends on how much fluid there is and how quickly it comes out. This can help reduce the ascites in the short term, but often the fluid will come back.

- **Long term drain**

This type of drain (also a small tube) can stay in for as long as needed and can be looked after at home. This can reduce the number of times you have to come to the hospital, and usually involves a district nurse coming in once or twice a week to drain the fluid.

Alongside draining the fluid, water tablets (diuretics), chemotherapy and other types of cancer therapies can also help control the fluid.

The Mesothelioma UK leaflet "Ascites" will give you further information.

### Constipation and Diarrhoea

**Constipation:** your bowels may stop working as often as is normal for you. With peritoneal mesothelioma, this can be caused by a number of things. Extra pressure in your abdomen caused by tumour or extra fluid can alter the way your bowels work. Sometimes it can cause a blockage in your bowel, causing a bowel obstruction. Obstruction means that you cannot have a bowel motion, and it can be painful. It can also make you feel sick or vomit. If any of these things happen you should always seek medical advice straight away from your doctor or nurse. If your bowel is obstructed, then you will have to go into hospital so that it can be investigated further.

Poor fluid and food intake and lack of roughage such as bran or fibre (which is contained in beans, cereals, fruit, vegetables or dried fruits) can all make constipation worse. Lack of exercise can also slow down your bowels.

Not everyone has their bowels open every day, so we will

take into account what is normal for you when we assess your bowels.

Some suggestions to help with these problems can include

- Drinking eight to ten glasses of fluid a day. This can be anything, but drinks without caffeine and alcohol are best, as both of these can increase the amount you urinate, meaning that you absorb less fluid to help your bowels work
- Eat regular meals even if they are small. This encourages your bowels to keep moving
- Try to include some fibre in your diet, such as fruit and vegetables with their skins on, bananas, dried fruits such as prunes or apricots, brown bread, brown rice or whole-wheat pasta
- Do not ignore the urge to go to the toilet

Some medications can cause constipation. In this case it might be recommended that you try a regular laxative to help, as well as increasing your fibre intake.

There are different types of laxatives that work in different ways. Which one you use depends on the problems you are experiencing. Therefore it is advisable to discuss it with your doctor, nurse or pharmacist.

**Diarrhoea** is when you pass loose stools or have your bowels open more than is normal for you.

In the same way as the mesothelioma in the abdomen can cause constipation by disrupting the way the bowel works, it can also cause you to have diarrhoea. Diarrhoea can also be caused by an infection or a parasite, and some medications or chemotherapy. Let your doctor or nurse know if you have diarrhoea, so that they can send a sample off for testing if necessary. Diarrhoea can cause you to become dehydrated, so try to drink plenty of fluids containing salt, water and sugar. These can include, mixed fruit juice and water, flavoured drinks or soups. You can also use special hydration liquids but speak to your doctor, nurse or pharmacist about these.

If the diarrhoea is caused by your mesothelioma and is an ongoing problem, medications can be used to slow the bowel down. Your doctor can prescribe these for you.

### Nausea and Vomiting

The feeling of sickness (**nausea**), or being sick (**vomiting**) can happen for a number of reasons. Finding the reason for the sickness is usually the best way to treat it, either by relieving the problem if this is possible, or by working out the best type of anti-sickness medication to try. It is always worth discussing this with your doctor, nurse or pharmacist so that they can advise you.

With peritoneal mesothelioma, the tumour and ascites in the abdomen can squash the internal organs including the stomach. This can make you feel nauseous or it can make you feel as if you have indigestion. Being constipated can also make you feel sick, as can some chemotherapy drugs and other medication such as antibiotics or painkillers.

Advise your doctor or nurse immediately if you are being very sick as you may need help to replace the fluid that you are losing. You may also need further investigations such as an X-ray or scan of your abdomen to make sure that the tumour is not obstructing your bowel.

Your doctor may want to do a blood test to see if there is another reason for your nausea, as sometimes the salts in your blood can be affected by the mesothelioma or the treatments you are on, causing you to feel sick.

**Indigestion** is pain or discomfort in your upper abdomen or a burning pain behind your breastbone. It can make you bring up wind and feel nauseous. It can also be described as “acid” or “reflux”, and food or fluid may come up into your gullet. Some medications and foods can make indigestion worse, so it is worth asking your doctor, nurse or pharmacist about this. Anxiety can also be a factor.

There are medications that can help with indigestion depending on the cause of it, so ask for advice.

### Loss of Appetite and Weight Loss

Nausea, constipation and diarrhoea can all contribute to **weight loss**. Sometimes, if you have extra pressure in your abdomen, you will feel full much sooner than normal, and this will also make you eat less. With mesothelioma you can still lose weight even if you are eating normally.

For further information on this, see the Mesothelioma UK booklet **“Mesothelioma and Diet”**, or ask your doctor or nurse if you can see a dietitian.

### Fatigue

**Fatigue** is another word for feeling tired and lacking energy. It is very common in people with mesothelioma, affecting as many as nine out of ten. Fatigue can be acute (short lived and reversible), or it can be chronic (longer lasting and caused by an underlying illness). Fatigue can be due to

many reasons. Mesothelioma can cause changes in your body that can lead to tiredness. Not eating very well, lack of sleep and exercise, certain pain killers, chemotherapy and anxiety can all contribute to fatigue.

Fatigue can be very frustrating for you and your family, as you cannot do all the things you would like to do. It can make you feel less good about yourself and your role within your family group.

This section aims to identify some of the reasons for fatigue and suggest some ways to try to manage it.

There is increasing evidence to show that some activity can help to improve how you feel and how you cope with treatment. Activity can help with a number of things, it can strengthen your muscles, joints and bones, help with your balance and look after your heart, it can improve your mood, reduce anxiety, help you eat and sleep better and decrease your chances of becoming constipated.

Activity does not always mean going to the gym, running long distances or generally doing intensive exercise, it can be simple things like going for a short walk or even staying out of bed longer than normal.

If you are on any form of treatment, you may not be able to do as much, and this is where being able to pace yourself becomes important. Pacing is knowing how much to do without exhausting yourself. There have been some research studies done with breast, bowel and prostate cancer patients which show that walking a few hours a week helps with the cancer as well as helping how you feel.

The level of exercise you will be able to take depends on how fit and active you were before your mesothelioma was diagnosed and how it affects you. Ideally it is recommended that people do 2 ½ hours moderate exercise a week. However it is always best to start slowly and build up. Look at what you can do at the moment: if it is walking up the garden and

back, do that every day for a week if you can, from there go a bit further, and build it up this way. If you find that you spend all day sitting in a chair, look at some of the chair-based exercises on the Macmillan DVD “Get Active Feel Good”: these can strengthen your muscles and flexibility, and enable you to do a bit more.

Always stop exercising if you get any sudden symptoms such as feeling dizzy, getting pain, a fast heartbeat, sickness, headache or uncomfortable breathlessness.

You can get advice about exercise from a physiotherapist, an occupational therapist or nurse, although you may need to ask for a referral for this. You can ask if there is a local exercise scheme for people with cancer, or a local support group. Your hospice will also often have access to physiotherapists and occupational therapists.

### Sweating

Sweating particularly at night is fairly common with mesothelioma, and can have a big impact on daily

life. They can soak your bedclothes and bed linen and disturb your sleep, making you feel more tired.

Different medications are thought to help, and this can be discussed with your doctor or nurse. Chemotherapy treatments can also sometimes help by controlling the activity of the tumour.

Things that can help include

- Using a fan in the bedroom, opening the windows
- Using only bed linen and nightclothes made of natural fibres, such as cotton.
- Trying temperature regulating pillow and mattress covers
- Having a lighter quilt or other bedding.

If you are having chemotherapy, make sure that you do not have a high temperature or fever if you are sweating, indicating that you might have an infection. If you do have a high temperature, you will need to contact your cancer centre immediately.

### Your Feelings

For many people, having a diagnosis of mesothelioma can be overwhelming, and will affect their lives in many ways. This can be in a practical, everyday way, but it can also affect how you feel about your life, your relationships, your work and your finances. All of these can lead to uncertainty, fear, a loss of control, and can affect your ability to cope with your mesothelioma diagnosis.

You may have many feelings when you find out that you have mesothelioma, this can affect how you behave and relate to other people. You may want to be alone, you may want your family and friends around you, there is no right or wrong way to react, and that reaction will be individual to you.

Sometimes feelings can be so overwhelming that they prevent you managing day to day, this can be a worry to you and those around you, and at this point you may need to help to address these feelings.

When talking about low mood, it can mean lots of things. It is understandable to feel upset about your mesothelioma as you have to think about very serious issues, but for many people, they will carry on with their lives despite this. If a low mood is affecting you all the time over a long period, and stops you doing things, it may be worth talking to someone about it.

Talking about your feelings is usually a good place to start. Talking about how you feel, what worries or frightens you, can sometimes help you practically and emotionally. For some people this can be very difficult, as we are usually in control and can cope with most situations. For some people it is frightening to talk about their mesothelioma, either because they may get upset or may upset others, they may appear demanding, often with a desire to protect those people close to them.

For a lot of people, talking to friends and family is enough, but

for some, talking to their doctor or nurse is easier and feels safer. Your doctor or nurse can also talk about other people who may be able to help you and introduce you to them or refer you to them. This can include specialist counsellors, physiotherapists, occupational therapists, or people who provide complementary therapies such as massage, reflexology or relaxation.

Ask your nurse, local asbestos victim support group or your cancer information centre if there are any local support groups. These are groups where you can meet other people with mesothelioma who may be able to understand how you are feeling. These groups are usually open to carers, partners and families as well. They often include practical education on related issues, but also provide a social space where you can meet other people in a similar situation to you. They are often run by local asbestos victim support groups and specialist mesothelioma nurses. If you do not have a

specialist mesothelioma support group in your area, there may be other groups that you could attend which may be relevant to you, or that you would feel more comfortable attending.

**Mesothelioma UK** have an up to date list of support groups on their website.

People often worry about asking for support, but there is nothing wrong with this. Ask yourself “what is the worst that can happen if I do”? Generally those close to you will want to help and support you in whatever way they can, and this will help you manage practically, and allow you to discuss issues with others. Not all of your conversations have to be about serious things, you can reserve these for when you are comfortable or when you need to.

Some people do not want to talk at all, and prefer to carry on as normal, giving little attention to their mesothelioma. There is nothing wrong with this, as long as help and support can be found and accessed if needed.

If you find that your mood is low most of the time, ask yourself if you regularly have these feelings

- Fatigue
- Feel no pleasure in activities
- Cry a lot
- Have trouble concentrating
- Are often irritable
- Not sleeping and waking early
- Sleeping more than usual
- Loss of sexual desire
- Feel less affectionate

It would be worth talking to your doctor or nurse as you may have symptoms of depression. This can be helped by referral to a clinical psychologist, a counsellor or sometimes a psychiatrist. Your GP might recommend anti-depressant tablets. There is always help and support for you, whatever your situation, so it is always worth asking about it.

Sometimes it helps to write a diary of how you are feeling each day, this can help find a reason for low mood, and enable the best help possible to be accessed.

### References

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### My Contacts

My doctor is

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My lung cancer nurse is

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My mesothelioma nurse is

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My palliative care nurse is

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My local support  
group contact

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Others

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### Useful Contacts

#### **Mesothelioma UK**

0800 169 2409

[info@mesothelioma.uk.com](mailto:info@mesothelioma.uk.com)

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

#### Further Useful Booklets

Mesothelioma UK produce a wide range of information you might find useful, but in particular, these may help along with this booklet

- What is Mesothelioma?
- Mesothelioma Support Services
- Diet and Mesothelioma
- Ascites