

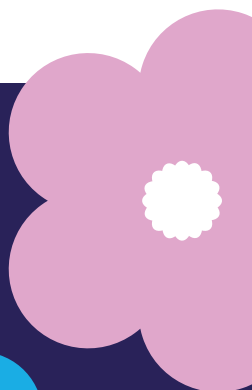
Peritoneal Mesothelioma



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. Peritoneal mesothelioma is a primary tumour in the peritoneum, that is the tumour originates from the peritoneal lining. Like mesothelioma arising in

the lining of the ribcage (pleural mesothelioma), in some people peritoneal mesothelioma can be caused by exposure to asbestos, although the links with asbestos are less clear and a number of patients have no history of asbestos exposure. Peritoneal mesothelioma is much less common than pleural mesothelioma and though the precise figures are unknown, peritoneal mesothelioma probably represents no more than 7-10% of all mesotheliomas.

Peritoneal Mesothelioma Types

Peritoneal mesothelioma is categorised into three groups. Diffuse malignant peritoneal mesothelioma

(DMPM), low-grade peritoneal mesothelioma (LGPM) and localised malignant mesothelioma. The three groups have different treatment regimes.

Diffuse Malignant Peritoneal Mesothelioma

DMPM includes epithelioid, sarcomatoid and biphasic. Malignant means that the tumour is made of cancer cells. They are abnormal and grow uncontrollably. DMPM is likely to spread throughout the abdomen. The majority of DMPM's are treated with palliative systemic anti-cancer treatments.

- **Epithelioid** is the most common subtype.

Epithelioid is slow to spread and patients may not experience severe symptoms until a later stage of disease.

- **Sarcomatoid** is less common. It tends to progress more quickly and has a poorer outcome from treatment.
- **Biphasic (mixed epithelial-sarcomatoid)** is uncommon. It's more aggressive than epithelioid but grows more slowly than sarcomatoid mesothelioma.

Low Grade Peritoneal Mesothelioma

LGPM includes multicystic mesothelioma and well-differentiated papillary

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mesothelioma. Low grade cells look more like normal cells and tend to grow and spread more slowly than high grade cancer cells. LGPM does not invade nearby tissues or spread to other areas of the body and these are the less aggressive forms of peritoneal mesothelioma.

● Multicystic

Mesothelioma (MM) is an uncommon tumour, estimated to account for 3-5% of all cases of peritoneal mesothelioma. MM are fluid-filled cysts that have thin translucent walls. These tumours can fill the abdominal cavity and cause symptoms. The common symptoms for MM are abdominal pain,

tenderness, swelling, constipation and infertility. MM predominantly affects women of reproductive age but it also affects men and can occur at any age. The disease is slow growing in the majority of cases and it is generally recommended that patients have a systematic clinical follow-up, possibly for life, to monitor the disease (surveillance). For disease which is extensive a surgical approach combining cytoreductive surgery (CRS) and hyperthermic intraperitoneal chemotherapy (HIPEC) can be used.

- **Well-differentiated papillary peritoneal mesothelioma (WDPM)** is rare. It is often discovered incidentally. WDPM predominantly affects women of reproductive age. The disease is generally indolent but in some patients has malignant potential. Clinical details and radiological images are used together with a tissue biopsy to gain a diagnosis and to rule out malignant features. They tend not to spread to the lymph nodes or via the blood stream. Symptoms experienced can be abdominal pain and ascites. Treatment for WDPM can vary from surveillance

without any treatment to systemic anti-cancer treatment.

Localised Malignant Mesothelioma

Very rarely, a solitary tumour otherwise resembling typical malignant mesothelioma may be found. Called "localised malignant mesothelioma", it is not often seen and is not classed as a diffuse disease.

It can be treated with an operation to remove the tumour. This aims to give a cure (the mass is removed with clear margins on the histology report). Histology alone cannot be used to diagnose localised malignant mesothelioma.

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Other evidence is needed, such as radiological imaging reporting no diffuse thickening or diffuse nodularity seen and surgical notes. If there is evidence in the future to suggest a recurrence or metastases then it would be re-classified as diffuse malignant mesothelioma.

How is peritoneal mesothelioma diagnosed?

People who develop 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. The procedure is referred to as “minimally invasive” or “keyhole” surgery. The surgeon makes one or two small cuts in the skin but the patient has to have a general anaesthetic as the abdomen has to be filled with gas to see inside.

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 samples are then sent off

to the laboratory to be looked at under a microscope by a pathologist.

Treatment

The choice of treatment for peritoneal mesothelioma depends on a number of factors including general fitness, other illnesses, which subtype of peritoneal mesothelioma and how advanced the disease is. There are various treatments options which include chemotherapy, surgery, surveillance and medication.

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. They work by

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disrupting the growth of the cancer cells.

Chemotherapy for mesothelioma is used in an attempt to shrink the disease but it will not cure the cancer. It can help to improve symptoms for some people and 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.

The chemotherapy drugs that may be used for the treatment of mesothelioma include Cisplatin (Platinol), Carboplatin (Paraplatin), Gemcitabine (Gemzar), Pemetrexed (Alimta) and Vinorelbine (Navelbine).

The Macmillan Cancer Support website contains information about individual chemotherapy drugs including how each drug is given and possible side effects that may be experienced with each drug.

Surgery

A small number of selected cases may benefit from surgery for peritoneal mesothelioma and this is performed in a specialist centre. It is called complete Cytoreduction Surgery (CRS). Hyperthermic Intraperitoneal Chemotherapy (HIPEC, heated chemotherapy) is sometimes put in the abdominal space at the same time as the surgery.

The aim of the surgery is to remove all of the visible disease. Palliative tumour “debulking” surgical procedures can be done to relieve symptoms where complete CRS is not indicated.

Symptom Management

Peritoneal mesothelioma is often diagnosed when the disease is quite advanced. It is important therefore to try to help manage and control symptoms. Doctors and nurses who specialise in symptom management (Palliative Care Teams) are recommended for all patients.

Surveillance

The LGPM groups which are not causing symptoms

nor have extensive disease will usually be monitored by regular clinical follow-up and scanning at their hospital.

Clinical Trials

Some treatments are available through clinical trials. Ask your consultant or specialist nurse for information.

A clinical trial is a research study designed to evaluate new or existing treatments. People who enter a clinical trial are among the first to receive new treatments before they become widely available. Because this research often leads to improved treatments, clinical trials play a key role in advancing the treatment for

mesothelioma.

Immunotherapy

Immunotherapy is now a standard treatment for some cancers such as melanoma and lung cancer. Early studies indicate it is also a useful treatment for mesothelioma. There are various clinical trials open in the UK that include immunotherapy. For further information on this, see the Mesothelioma UK booklet “Immunotherapy”.

Symptoms and how to manage them

The symptoms of peritoneal mesothelioma can include discomfort or pain, swollen abdomen, constipation or diarrhoea, feeling sick (nausea) or being sick, indigestion, loss of appetite, 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.

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. 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.

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.

For further information on this, see the Macmillan booklet “Managing Cancer Pain”.

Ascites

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.

The symptoms of ascites can be distressing. The abdomen may become

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very swollen and distended, which can be uncomfortable or painful. It can also cause difficulty in getting comfortable, sitting up or walking. It can make you feel tired (lethargic) and breathless. It may cause you to feel nauseous or may make you physically sick. It may give you indigestion and you may lose your appetite.

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 guides the doctors to where the fluid is located. Putting a tube into the abdomen to drain

it is known as a procedure called paracentesis. The drain is usually inserted by a doctor and the procedure can be done in the ward or in the clinic. Sometimes a small amount of fluid can be drained in the clinic. If there is a large amount of fluid however, the procedure may need to be carried out in hospital under the supervision of the doctors and nurses and the drain may stay in place for a period of 2–3 days. It is possible for the ascites to build up again and drainage may need to be carried out more than once.

If the fluid becomes very troublesome and builds up on a regular basis, it may

be possible to insert a permanent drainage tube under the skin of your abdomen which will 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.

For further information on this, see the Mesothelioma UK booklet “Ascites”.

Bowel Changes

Obstruction

Your “normal” bowel habit may change. 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 cause sickness and make you feel out of breath. The obstruction can be caused by the mesothelioma itself or in some cases by very advanced ascites (the fluid that accumulates in your

abdomen). If any of these things happen it is important that you 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.

Diarrhoea

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 have diarrhoea as a side-effect. 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.

Constipation

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.

Some suggestions to help with these problems can include:

- Drinking eight to ten glasses of fluid a day. This can be any type of fluid, 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

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depends on the problems you are experiencing. Therefore it is advisable to discuss it with your doctor, nurse or pharmacist.

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. The mesothelioma you can cause weight loss 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.

Activity can help with fatigue along 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.

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.

For further information on this, see the Macmillan booklet “Coping with Fatigue (Tiredness)”.

Sweating

Why and how excessive sweating occurs in people with mesothelioma is not exactly clear. 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 sometimes help to control the sweating.

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.
- Avoiding drinks with caffeine, especially if sweating is worse at night.

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

For further information on this, see the Mesothelioma UK booklet “Sweating”.

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. The feelings can be so overwhelming that they may prevent you managing day to day. 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.

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 a lot of people, talking to friends and family is enough, but for some, talking to a professional is easier and feels safer. Professionals include your doctor and nurse, counsellors, physiotherapists, occupational therapists, or people who provide complementary therapies such as massage, reflexology or relaxation.

Ask your nurse 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. The Mesothelioma UK website has an up to date list of support groups on their website and there is an online virtual support group specifically for peritoneal mesothelioma.

For further information on this, see the Macmillan booklet “Coping with your Emotions”.

References

- British Nutrition Foundation:
www.nutrition.org.uk
- Macmillan Cancer Support:
www.macmillan.org.uk
– Booklets: Managing Cancer Pain, Coping with Fatigue (Tiredness), Coping with your Emotions, Maintaining a Healthy Lifestyle, Move More, Physical Activity and Cancer Treatment
- NHS: www.nhs.uk – Constipation, laxatives.
- Cancer Research UK:
www.cancerresearchuk.org – About Mesothelioma, Coping with Cancer, Bowels, Blocked Bowel.

Further Useful Information

10 Steps to an Active You
Leaflet

www.bdct.nhs.uk/wp-content/uploads/2019/06/Leaflet-10StepstoActiveYouWalking_PHE.pdf

Macmillan Move More:
Your Complete Guide to
Becoming More Active

www.macmillan.org.uk/documents/cancerinfo/physicalactivity/movemore.pdf

Public Health England
“One You”

www.nhs.uk/oneyou/for-your-body/

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