



The Mesothelioma Handbook

Dr Helen Clayson



Information for patients, family carers
and healthcare professionals

The June Hancock
Mesothelioma
Research
Fund

About the author



Dr Helen Clayson has been involved in the care of people with mesothelioma for 30 years, looking after them in their homes, hospice and hospital. She worked as a GP and as a palliative medicine physician in hospice (including Hospice at Home) and hospital in South Cumbria. The local shipyard town, Barrow-in-Furness, has the sad distinction of the highest incidence of mesothelioma in men in England caused by use of asbestos in the shipbuilding and heavy engineering industries in the past.

Frustrated by the inadequate information in medical publications about the treatment of people with mesothelioma, Dr Clayson obtained a grant in 1999 from the Royal College of General Practitioners to conduct a doctoral study entitled 'The experience of pleural mesothelioma in Northern England'. This revealed serious problems in the care of people suffering from mesothelioma, and prompted her in 2005 to start a local support group that is now Cumbria Asbestos-Related Disease Support (CARDS). The study also led to extensive lecturing and teaching in the UK and overseas. Dr Clayson continues to work in research and education concerning asbestos-related diseases - including a training programme in Japan and an asbestosis project in India. This handbook is based on her experience and research.

Dedication

This handbook is dedicated to all those affected by mesothelioma.

Disclaimer

The handbook is intended to provide information about mesothelioma. The information found on these pages is not meant to provide specific medical advice, or to replace the continuing care, guidance and supervision provided by the doctors and other members of the healthcare team. Patients should always seek proper medical advice and maintain regular communication with their medical advisers.

Every effort has been made to ensure that the contents reflect the situation at the date of publication.

Dr Clayson has no connection with the asbestos industry or any legal or insurance organisation that supports the industry.

Appreciation

A special thank you for their encouragement and support in the production of this Handbook to Dr Kate Hill, Trustee, June Hancock Mesothelioma Research Fund; Dr Yasuko Sarah Nagamatsu, Associate Professor, St Luke's International University, Tokyo; and Laurie Kazan-Allen, co-ordinator of the International Ban Asbestos Secretariat.



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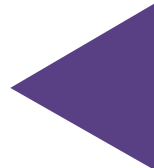
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Introduction



Patients with mesothelioma say that having reliable information about the condition and receiving good care at home, from family members alongside community nurses, can make a huge difference to their experience of the illness. The diagnosis of mesothelioma usually comes as a shock, but those affected by this illness are not alone: this handbook has been developed in collaboration with people who have mesothelioma, family members and healthcare professionals involved in their care and members of asbestos victims support groups.

This handbook is written with the intention of providing straightforward and comprehensive information. Professional knowledge of the condition is variable as it is very uncommon in some areas. However, the information provided here is based on considerable experience in the medical and nursing care of sufferers from mesothelioma and in the support of their relatives. People with mesothelioma and their family carers want different types and quantities of information. Some people with mesothelioma might feel that they receive sufficient information from their doctors. Family carers are 'partners in care' with community healthcare staff and, as such, should have access to as much information as they want and need.

The term 'family carer' is used throughout the handbook for those close relatives or friends who might be involved in the care of someone with mesothelioma, for example, wife, husband, daughter, son, step-relative, partner or close acquaintance. Many close relatives have said that they do not regard themselves as 'carers' as they are simply 'doing what you naturally do in a family'. However, for convenience and brevity, the term 'family carer' is useful. It also distinguishes 'informal' carers ie family or friends, from 'professional' or 'formal' carers ie those who are healthcare professionals.

This handbook is not meant to be read cover to cover, you can chose how much or how little you need to read, according to your situation. Particularly at the time of diagnosis there is a lot to take in, and so you might prefer to dip in and out of the handbook. There is a lot of information presented here because mesothelioma affects different people in different ways. Every effort has been made to use straightforward language and to explain any specialist terms. If you find some of the content rather difficult or technical please discuss any queries with your Macmillan or lung cancer nurse, GP or specialist. You can use the book to prompt questions that you might need to ask.

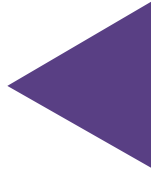
Information that is mainly for nurses and other healthcare professionals is placed at the end of some sections and has a purple background and page heading. The term 'community nurses' includes District Nurses, Practice nurses and Hospice at Home nurses; other healthcare staff such as GPs, junior doctors, physiotherapists and occupational therapists might also find this handbook useful.







Understanding mesothelioma



Mesothelioma is a cancer affecting the mesothelial membranes; these are thin filmy layers of lubricating tissue that enable internal organs to glide smoothly against each other as the body moves. The pleural membrane (the pleura) tightly surrounds each lung and a second layer lines the inside of the chest wall; the pleura normally produce a small amount of lubricating pleural fluid that keeps the lungs mobile inside the chest during breathing. In the abdomen the peritoneum is the membrane that surrounds the intestines and other abdominal organs; it also lines the abdominal cavity and produces a small amount of peritoneal fluid to keep the organs smoothly mobile. Similarly, the pericardium is the lubricating membrane that surrounds the heart. Mesothelioma of the pleural membrane is the most common form; it occurs less often in the peritoneum and occasionally affects the pericardium. Very rarely mesothelioma develops in the membrane surrounding the testicles.

Mesothelioma is almost invariably caused by exposure to asbestos fibres and in the majority of cases this exposure occurs in the workplace. In some cases asbestos exposure affects family members due to asbestos fibres being carried into the home on work-clothes. Environmental exposure in the UK occurs in areas surrounding former asbestos industry sites. Traditional industries that used large amounts of asbestos materials, usually as insulation against heat, included shipbuilding and repair, train production and maintenance, other heavy engineering and asbestos textile production. These industries have declined but there are now huge amounts of asbestos in public and domestic buildings, particularly those built or refurbished before 1990. This explains why mesothelioma is increasingly affecting tradesmen, such as joiners, painter/decorators, electricians and demolition workers, who work on the structure of asbestos-containing buildings. Although import and use of asbestos was totally banned in the UK from 1999, and health and safety regulations have been introduced to protect the workforce, there continues to be widespread flouting of the regulations and much ignorance about the health hazards of asbestos. The number of UK cases of mesothelioma continues to increase; there were more than 2500 cases in 2012. Mesothelioma cases in Australia are now being attributed to asbestos exposure from DIY activities in houses constructed using asbestos-containing materials. In Asia, particularly India and China, huge amounts of asbestos are still imported and used. Inevitably this will create a serious public health problem, as yet not acknowledged in those countries.

Asbestos fibres that are breathed in accumulate in the lungs where, over many years, they cause inflammation and other long-term changes that can eventually lead to cancer (mesothelioma) developing in the pleura. In addition, people who both smoke and are exposed to asbestos have a very high risk of lung cancer (called asbestos-related lung cancer) due to the multiplying of the cancer risk by these two factors in combination. Asbestos causes other illnesses such as asbestosis, which is a slowly progressive fibrosis or scarring affecting the lung tissue. It also gives rise to pleural thickening which may extend around and constrict the lungs, causing difficulty with breathing, and, less seriously, causes pleural plaques which appear on chest x-rays as scarring on the pleura but do not usually create any serious problems.



Mesothelioma develops very slowly; it is usually 30 to 50 years between initial exposure to asbestos and the onset of symptoms, but it can then progress quite quickly. It can be difficult to diagnose because there is no simple way of differentiating mesothelioma from other diseases. Currently mesothelioma cannot be cured by the usual cancer treatments such as chemotherapy, radiotherapy or surgery, but these treatments can help to relieve symptoms and to slow progression of the disease.

There are different *subtypes* of mesothelioma. The names of the subtypes reflect the different appearances of the cells in the tumour (cancer). The subtype can only be identified by direct examination of tumour cells after they have been obtained by biopsy or sometimes from pleural fluid. In the UK the subtype is determined in about half of all the cases. The commonest subtype, *epithelioid* mesothelioma, usually has the best response to chemotherapy and the longest survival time. Unfortunately *sarcomatous* mesothelioma has a less good outlook, and *mixed* or *biphasic* mesothelioma has an outlook between the other two. As more becomes known about how the different subtypes vary in response to treatment it is likely that treatment decisions will be based on the subtype of mesothelioma – this is an example of ‘targeted therapy’ or ‘precision medicine’.

In this handbook most of the information refers to pleural mesothelioma, the commonest type, and the majority of research has been conducted in this illness. However most sections contain some information concerning peritoneal mesothelioma.

Reaching the diagnosis of mesothelioma

The first symptom of pleural mesothelioma is usually shortness of breath and/or a nagging chest pain. These symptoms prompt people to visit their GP, or less often, to attend an Accident and Emergency department. Shortness of breath is usually due to an accumulation of pleural fluid around the lung. Peritoneal mesothelioma often causes swelling of the abdomen due to accumulation of peritoneal fluid. Diagnosis might take time because there is not one test that on its own differentiates mesothelioma from other conditions. Fluid removed from around the lung or abdomen might not reveal the diagnosis. Biopsy (a small sample of tissue taken from the pleura or peritoneum, under an anaesthetic) is often required and even then it can be difficult to distinguish mesothelioma from other conditions. The process of obtaining a diagnosis is frequently frustrating and extremely worrying for patients and their families.

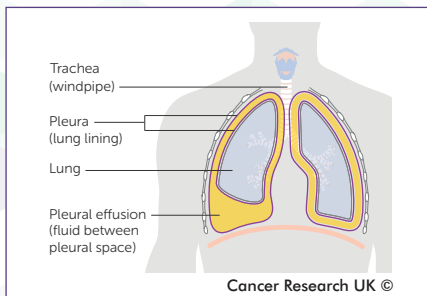


Figure 1: **Pleural effusion**

Diagram taken from the patient information website of Cancer Research UK:
www.cancerresearchuk.org/about-cancer/

People are usually in shock after learning the diagnosis and it can be hard for them to take in all the information that is given at this stage. Patients and their relatives should not be afraid to ask for the information to be repeated or for more time in which to make decisions. It could help to take written questions to appointments and to make notes of what is said in those consultations. Patients are entitled to receive information about the condition in writing if they wish. In some clinics consultations can be audio-recorded but that might need to be requested in advance.

Staging in mesothelioma

Patients might be told that the mesothelioma is at a particular stage. Stage 1 indicates early disease and Stage 4 the most advanced disease. Staging is an indication of how advanced the cancer is, whether or not it has spread from the original site and, if so, where it has spread to.

The stage is determined by scans such as CT (Computerised Tomography) or MRI (Magnetic Resonance Imaging). Staging can be used, alongside factors such as any other illnesses that the patient might be suffering from, to decide on the appropriate type of treatment. However, this is not straightforward in mesothelioma and there is continuing debate about the most commonly used staging system developed by the International Mesothelioma Interest Group (IMIG) (see Table 1).

Table 1: Staging in mesothelioma (brief summary of IMIG staging)

Stage	Description
1	The mesothelioma is only affecting the pleura on one side of the chest
1a	Only the outer layer of the pleura is affected
1b	Both the outer and inner layers of the pleura are affected
2	The mesothelioma affects both pleural layers in one side of the chest but the cancer has extended into the lung tissue or into the diaphragm muscle
3	The mesothelioma has spread from the pleura into the local lymph glands in the chest or into deeper tissues around the pleura such as the chest wall or the pericardium (the membrane around the heart)
4	The mesothelioma has extended beyond one side of the chest such as into the other side of the chest, into the spine or the pericardium (the membrane around the heart), into heart muscle, or into distant lymph nodes. Occasionally mesothelioma spreads into distant parts of the body, but this is rarely a significant problem in this disease in contrast to many other cancers in which 'secondaries' might need specific treatment.

The multi-disciplinary team (MDT)

A surprising number of experts are involved in the care of patients with any type of cancer. It is now recognised as best practice that a range of medical, nursing, surgical and other experts should meet regularly to discuss patients who have a diagnosis of cancer in order to provide the best care for them. Mesothelioma cases are usually discussed at a lung cancer and mesothelioma MDT meeting as soon as a diagnosis or suspected diagnosis is made. In some areas there are specific regional mesothelioma MDTs. Each case will be discussed at the MDT meeting in order to determine which type of treatment or further investigation is to be advised, based on the best evidence from research studies. Patients do not attend these meetings but will be informed of the advice regarding treatment by their specialist nurse or doctor. Sometimes, different treatment options will be presented. It is then up to the patient to decide how he or she wants to proceed with treatment. MDTs might also determine whether a patient is eligible to participate in any clinical trial of potential new treatment (see page 17).



The multi-disciplinary team usually includes:

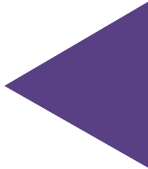
- 1) specialist lung cancer nurse/s (in 6 areas of the UK there are specific mesothelioma specialist nurses)
- 2) respiratory physician
- 3) pathologist (who works in a laboratory and examines the cells from biopsy samples)
- 4) cardiothoracic surgeon (who might be involved in obtaining pleural biopsies or conducting surgical procedures such as pleurodesis or pleurectomy: see the surgery section on page 15 for an explanation of these terms)
- 5) medical oncologist (who prescribes and supervises chemotherapy and targeted therapies)
- 6) clinical oncologist (responsible for all radiotherapy treatments)
- 7) radiologist (who specialises in x-rays, scans and some guided biopsies)
- 8) palliative care specialist (expert in control of symptoms and supportive care, often working in community, hospital and hospice)



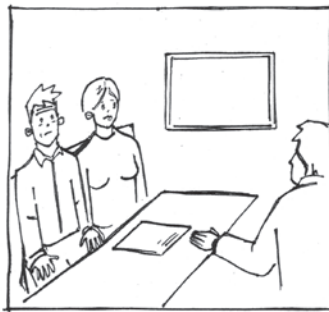




Cancer (oncological) treatments for mesothelioma



Chemotherapy with pemetrexed and cisplatin is recommended as standard treatment for mesothelioma in the UK but there is no national guidance about other types of treatments. Each case is different and every patient needs to have enough information to weigh up the pros and cons of the options. Some people decide not to have chemotherapy and that decision must be respected. Declining any treatment offered does not affect the right to good control of symptoms. Patients are entitled to change their minds about treatment at any stage during the illness. In the UK patients have the right to decline treatment but do not have any right to demand specific treatments. The types of treatments available through the NHS are determined by the results of research and the National Institute for Health and Care Excellence (NICE) produces treatment guidelines based on research evidence.



'There is a lot we can do to help treat your symptoms.....'

Chemotherapy

People with mesothelioma will usually be referred to an oncologist (cancer specialist) once the diagnosis has been made and following discussion in the MDT (see above). In most cases they will be offered chemotherapy with a combination of 2 medications: pemetrexed (trade name Alimta) and cisplatin or sometimes carboplatin. This is the standard chemotherapy that has been recommended for pleural mesothelioma by NICE. Chemotherapy offers modest benefit, not cure, therefore patients and their families need to understand the pros and cons of chemotherapy in order to make a decision about treatment. Patients who have received this combined chemotherapy as their initial treatment might be offered a different drug/s at a later stage; this is called 'second line chemotherapy'. New developments in treatment might be available in clinical trials – see later.



Chemotherapy drugs affect the growth of cancer cells and so they are intended to slow down the progression of mesothelioma. The current (2016) chemotherapy regime for mesothelioma, pemetrexed and cisplatin, is often tolerated quite well by patients. It is usually given by an intravenous drip as an outpatient procedure in the oncology or chemotherapy day unit. There is an interval of around 3 weeks between each infusion – each infusion and interval is called a cycle and patients often have 4 to 6 cycles if the medication is tolerated. Patients are then reviewed, sometimes with a scan to check response to treatment.

If mesothelioma is diagnosed when it is at an advanced stage the patient might be too ill to undergo chemotherapy or surgery. In any case, there is no evidence that these treatments are effective in this situation. Palliative care specialists provide control of symptoms in advanced disease and prompt referral to this service is helpful.

Chemotherapy side effects

Patients will be given a thorough explanation by the chemotherapy unit staff of any side effects to expect and how to respond if they should occur. Side effects tend to be temporary and go away once treatment has stopped. Some side effects are quite common and they are listed below:

- a) *Changes in the blood count.* Chemotherapy can cause reductions in white cells that fight infections, which will make patients more susceptible to infections, particularly 10 to 14 days after each treatment. This is a potentially serious side effect and might require treatment in hospital. Some patients become anaemic which might cause tiredness. Occasionally temporary reductions in platelets, the blood cells involved in making the blood clot, can cause bleeding such as nosebleeds or bleeding gums. It is rarely serious and medication can help.
- b) *Feeling and/or being sick* - medication will reduce these symptoms that usually stop after a few days
- c) *Diarrhoea* - this is usually temporary and responds to medication
- d) *Sore mouth or mouth ulcers* – these heal and can be relieved by medication
- e) *Fatigue* is a common symptom with chemotherapy. It is sensible to pace activities and not try to do too much during treatment. Patients soon get to understand how they feel at various times during each chemotherapy cycle and should plan their activities accordingly.
- f) *Hair thinning.* The drugs used to treat mesothelioma are unlikely to cause total hair loss but some thinning of the hair and change in texture are common and temporary.
- g) *Dry skin* can occur and will respond to simple moisturising creams.

Surgery

In some cases surgery might be recommended, particularly if the tumour is restricting the expansion and/or movement of the lung. The most likely surgery in the UK at this time is a procedure known as pleurectomy/decortication (PD). This operation removes the diseased pleura and any tumour that has spread into the lung and is sometimes referred to as a 'debulking' procedure. There are various types of pleurectomy/decortication and currently the term covers a range of similar procedures.

Radical, or extensive surgery (EPP – extra-pleural pneumonectomy) is less commonly performed now following the results of a UK clinical trial (the MARS trial: Mesothelioma and Radical Surgery, 2011). EPP involves the surgical removal of the pleura, the pericardium around the heart, the lung, and the diaphragm on the affected side. The MARS trial concluded that this major surgery did not result in any significant benefit to patients with pleural mesothelioma but caused reduced quality of life. However, in some countries, eg Japan, which have not undertaken the same research, EPP is still commonly performed. There is ongoing debate internationally about the place of extensive (ie radical) surgery in fit patients who present with very early disease. If surgery is performed on this type of patient it will be as part of a comprehensive treatment plan that includes chemotherapy and radiotherapy – this is called multi-modality treatment.

Surgery might also be advised in peritoneal (abdominal) mesothelioma. This involves a similar 'debulking' operation that aims to remove as much as possible of the cancer. Only a few centres in the UK offer this treatment (Mesothelioma UK has details of the centres).



Radiotherapy

Mesothelioma does not respond well to radiotherapy but in certain situations it might be helpful. It is common for radiotherapy to be given to the site of any chest wall incisions eg for biopsy or insertion of a drain, in an attempt to prevent the cancer spreading outwards along the track. If this does occur it can result in a lump on the chest wall. Radiotherapy is very effective at reducing any pain or discomfort from such a lump. Radiotherapy is also used as part of multi-modality (several treatments in combination) therapy alongside surgery and chemotherapy. There is some research now that suggests low dose radiotherapy might be a useful additional treatment for chest pain (From the SYSTEMS 2 trial).

Radiotherapy in mesothelioma rarely causes serious side effects because relatively low doses are used and treatment is directed at the pleura on the outside of the lungs rather than at lung tissue that can be damaged by radiotherapy. Temporary side effects may include tiredness, skin reaction, difficulty swallowing and nausea. Patients should discuss any of these problems with radiotherapy staff.

Palliative care

World Health Organisation definition of palliative care:

Palliative care ensures the prevention and relief of suffering by early identification and impeccable assessment and treatment of pain and other problems - physical, psychosocial and spiritual. Palliative care improves the quality of life of patients and their families when they are facing the problems associated with life-threatening illness,.

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends to neither hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families;
- Enhances quality of life and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications.

Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

Increasingly provided alongside cancer treatments every patient with mesothelioma should have access to a palliative care team to benefit from their expertise in the management of difficult physical and psychological symptoms and a holistic approach to the care of patients and their loved ones.

Palliative care delivers expert control of symptoms, such as pain and breathlessness, together with comprehensive support for patients and their families, personalised according to individual needs and circumstances. Palliative care teams include a variety of professionals such as consultants in palliative medicine, clinical nurse specialists eg lung cancer and Macmillan nurses, occupational therapists, physiotherapists, psychologists, complementary and creative therapists, spiritual care providers and counsellors. Patients at all stages of the illness and their families can benefit from palliative care in hospitals, from community-based services including Hospice at Home and in hospices. Palliative care is increasingly provided at the same time as cancer treatments such as chemotherapy and radiotherapy. It is particularly helpful for those who have physical symptoms, for example breathlessness or pain that are difficult to control, or for those who are struggling with psychological distress such as anxiety. Family members are also offered support including complementary therapies, counselling or practical advice and assistance in caring for someone with mesothelioma.

Patients with very advanced disease might not be suitable for cancer treatments and others will have chosen not to have chemotherapy. Palliative care is essential in these cases and can greatly improve quality of life as well as offering practical and emotional support to family members.

Research and clinical trials

Scientists are working to find new treatments that will slow down or cure mesothelioma. Currently, research priorities include a) developing new drugs that will slow down the growth of the cancer, b) finding ways of boosting the immune system to destroy the cancer cells, and c) identifying 'biomarkers' (These are substances in body fluids or tissue that can predict an individual's interaction with the disease such as the likely response to treatment or predict their risk of developing the disease).

People who participate in clinical trials to test new drugs tend to do so for the following reasons:

- They believe that although the new treatment probably won't help them it will be useful for patients in the future, or
- They hope that they might benefit from the new treatment (although they know that they might not receive it), and at no cost, or
- They want to benefit from the additional medical attention that is part of the trial protocol, such as more frequent monitoring and follow up

Patients might be invited to participate in clinical trials in mesothelioma. Participation is entirely voluntary. In clinical trials a new drug is commonly compared with either an existing treatment or an inactive substance, known as a placebo. Participants in most trials will not be aware whether they are receiving the new drug, an existing drug or a placebo. In other words, entering a trial does not mean that a participant will



automatically receive the new treatment.

Some patients who have not been told about the possibility of taking part in a clinical trial might want to find out more; lung cancer nurses, oncologists and the following websites have details: www.nhs.uk and www.mesothelioma.uk.com

Anyone who might be suitable to be a trial participant will be given full information about it in order to make the decision about taking part. *Participants can withdraw at any stage if they wish, without any difficulty or disadvantage.* Not everyone will be suitable for participation in a clinical trial; people might be excluded if they have other significant illness or are very elderly or in very poor health.

It takes many years and massive funding to develop a new drug from the first idea to getting it to the patient. The process involves the 4 phases of clinical trials (Table 2):

Table 2: The 4 phases of clinical trials

Phase	Description
1	Basic information eg to determine the dosage and administration of the new drug
2	Safety and efficacy of the new treatment
3	Comparison of the new drug with current treatments or placebo (ie an inactive substance). If the new drug looks useful at this stage the pharmaceutical company will proceed to register it as a new drug
4	Large scale monitoring, looking for any unknown side-effects and interactions with other drugs



Questions that a patient might want to ask about the diagnosis and treatment

Where is the mesothelioma?

Has it spread and, if so, where to?

Can you tell me what stage it is?

Which subtype is it?

What are all the treatment options?

Is it better to opt for treatment now or should I wait and see how I get on?

What are the most likely benefits of any treatment?

Am I eligible for any clinical trials? If so, what would be involved?

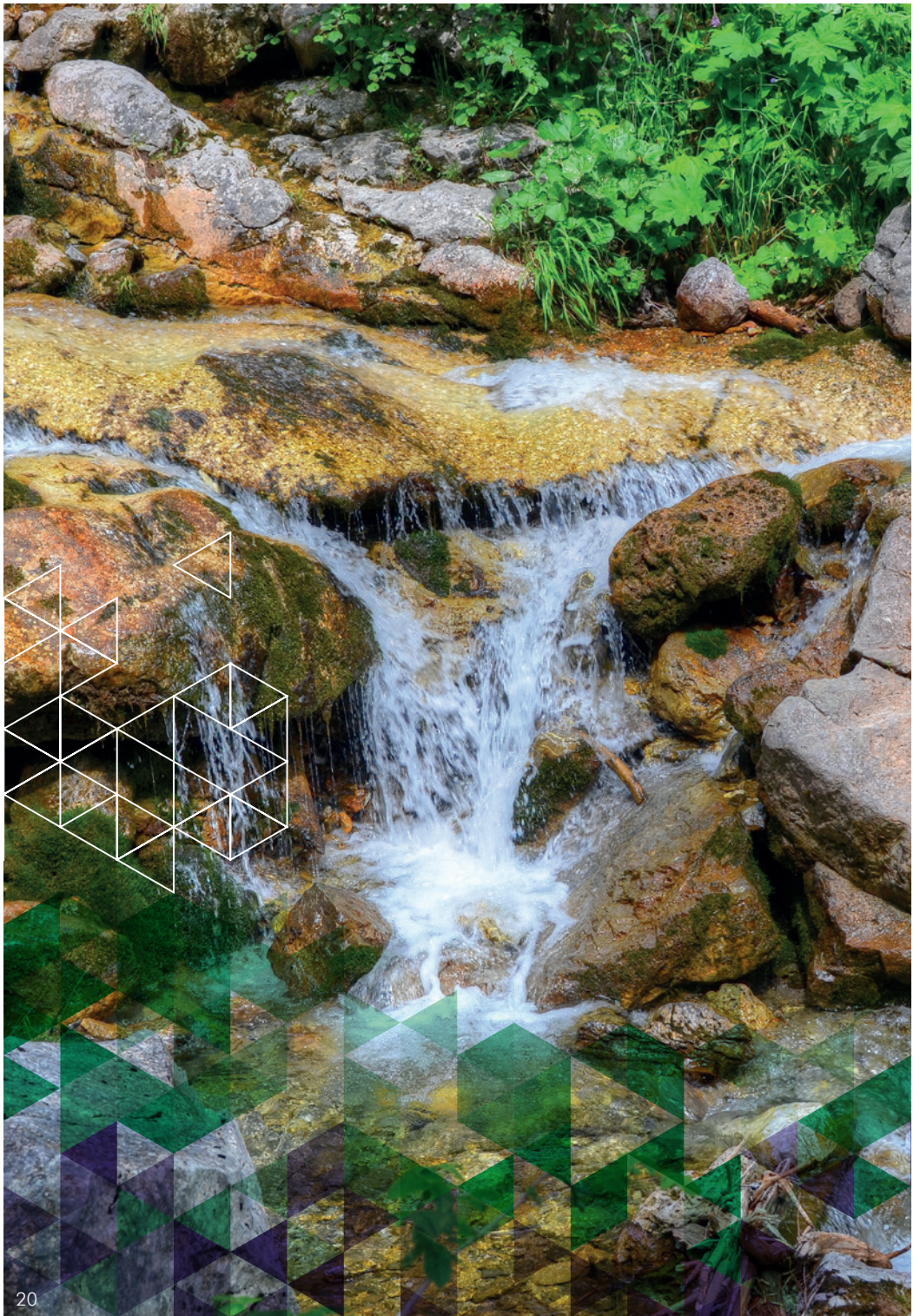
How can I find out more about any trials that I might be eligible for?

I am breathless. What is causing it and how can it be treated?

I am suffering from pain. What is causing it and how can it be treated?

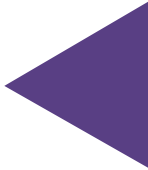
I would like to see a palliative care specialist. Will you arrange this?







Symptoms and their management in mesothelioma



Symptom control in mesothelioma is not always easy **but it is possible**. Not all patients will develop severe symptoms but it is better to treat symptoms as soon as possible to prevent them getting worse as the disease progresses. Patients should be referred **quickly** to a palliative medicine specialist or pain management service as soon as any symptoms prove difficult to control. The symptoms of mesothelioma can be more problematic than those of some other cancers. The causes of symptoms are often complex and they might not respond to simple remedies. However, quality of life can be greatly improved if good control of physical and psychological symptoms is achieved. This usually requires considering the full range of specialist palliative care interventions at an **early** stage. An early referral to palliative care introduces the patient to a team who might be important later in the illness. The GP or oncologist can easily arrange this and patients should not hesitate to ask for referral if it is not offered. Recent research *in lung cancer* suggests that early referral to palliative care is acceptable to patients, improves quality of life, and might even improve length of survival.

Three steps to good symptom management:

1. Do everything possible to relieve distressing physical and psychological symptoms.

Most people with mesothelioma will have access to a lung cancer clinical nurse specialist or will have been referred to a Macmillan nurse or palliative care team or, in a few areas, will have access to a mesothelioma clinical nurse specialist. These professionals all have specialised knowledge of the treatment of cancer symptoms. Patients and/or family carers should readily contact them for advice, particularly if symptoms do not respond to treatment. Urgent referral to a specialist in palliative medicine or pain management can be arranged if needed via the oncologist, GP or specialist nurse.

2. Understand what symptoms mean to the patient.

Healthcare professionals (and family carers) need to understand what is really troubling a person with mesothelioma so that they can address those anxieties, beliefs or assumptions. For example, someone might have specific fears about developing unbearable pain or suffering from severe breathlessness. Once the underlying anxiety is understood the healthcare team can explain how symptoms could be controlled if they were to develop. Having accurate information is key – the right amount of information at the right time for each individual. **Patients and their families must be prepared to ask questions - it is helpful to keep a written list of queries.** Patients are often reluctant to disclose their worries outside the family and so relatives might need to raise any concerns with the healthcare team.



3. Have a plan to cover all eventualities.

The condition of a person with mesothelioma can sometimes deteriorate suddenly, and family carers need to know how to access help, particularly during nights and weekends. Out-of-hours GP organisations should be informed about people with mesothelioma so that they can respond appropriately – the GP or community nurse should arrange this.



Patients and their families should have the following:

1. A list of emergency contact telephone numbers:

A page for a personal list of contact details is included at the back of this handbook.

- GP surgery
- Out-of-hours GP service
- Pharmacy
- District Nurse
- Lung cancer nurse
- Hospital
- Hospice

2. Information about a range of supportive services.

Patients (and their relatives) can benefit from a wide range of services eg pain clinics, psychological interventions including counselling, complementary therapies, chaplaincy, family support, and welfare benefits advice. In addition, hospice services including Hospice at Home are available if a person with advanced mesothelioma does not want to go into hospital or hospice, preferring to be cared for in his or her own home.

3. Contact details for the nearest asbestos victim support group (see Section 9)

Support groups can be a valuable source of information and assistance.

Patients with mesothelioma and their relatives often feel very isolated and greatly appreciate contact with people who understand their situation. Support groups also offer advice regarding State Benefits and help with completion of claim forms. They can also advise on how to engage an expert solicitor to deal with civil compensation claims.

4. In advanced disease a prescription for 'just in case' medications should be provided by the GP, palliative care team or hospice specialist. These should include medications for breathlessness and strong painkillers that might be needed if symptoms get worse. In most cases they are not needed if symptoms are monitored frequently and well-controlled. These medications must be kept in a safe place in the home. Having a supply of 'just in case' medications on hand for the GP or District Nurse to use if needed is very reassuring and much better than trying to find a pharmacy in the middle of the night or in a crisis (see 'Advance Care Planning' in Section 7).

5. Knowledge of the wishes and preferences of the patient. This information should be shared with the healthcare team. In advanced illness this is essential in order to achieve the best possible care in line with the patient's wishes (see Section 7).



Breathlessness in mesothelioma

Breathlessness is the most common symptom in pleural mesothelioma and is often the first sign that something is wrong. Most people experience this feeling at some stage in the illness but it varies in severity; a few people never become breathless.

Breathlessness occurs for many reasons, but in mesothelioma it is frequently caused by accumulation of fluid, called a **pleural effusion**, around one lung (see Figure 1). Healthy pleural membranes usually produce about 10mls (around 2 teaspoons) of pleural fluid to lubricate the movement of the lung inside the chest wall. In pleural mesothelioma the volume of fluid is greatly increased, sometimes several litres can accumulate. This interferes with the function of the lung. During breathing the lungs take oxygen into the body from the air that is breathed in and expel the waste gas, carbon dioxide, in the air that is breathed out; this is called gas exchange or transfer. A small pleural effusion will not interfere with the function of the lung. A large effusion causes pressure on the lung thus reducing the ability to exchange oxygen and carbon dioxide. The body compensates for this impairment by increasing the speed and force of breathing, this causes the sensation of breathlessness.

The experience of breathlessness

1. Breathlessness is a 'bio-psychosocial' phenomenon. In other words the sensation as experienced by patients is due to a combination of physical and psycho-emotional factors
2. Breathlessness crises cause fear of imminent death
3. Breathlessness is visible to others, causes social isolation due to lack of mobility, results in loss of control over life, and creates embarrassment and feelings of inadequacy
4. Despite high levels of anxiety, patients and relatives are frequently reluctant to call for help and often wait until desperate

From interviews with people who had breathlessness due to pleural mesothelioma (Clayson H, 2007)

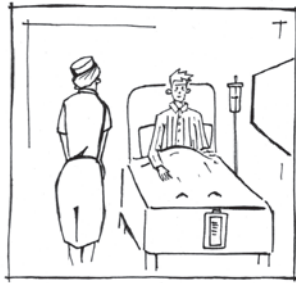
Managing breathlessness due to pleural effusion

Pleural aspiration (drainage)

Fluid around the lung can simply be drained off (a hospital procedure) but it tends to re-accumulate and this results in repeated admissions to hospital for aspiration. In advanced mesothelioma the fluid sometimes gets trapped in pockets around the lung and then it can be difficult to drain it all away. (This is called a **loculated effusion**).

Pleurodesis is a procedure that is performed in order to prevent recurrent pleural effusions. This involves instilling sterile medical talc between the pleural layers. The talc stimulates irritation that results in the two pleural layers becoming stuck together. Once this happens there is no space in which fluid can accumulate. Following the procedure patients can experience chest pain and flu-like symptoms for a few days.

Pleurectomy is a surgical procedure in which part of the pleural membrane is removed. The resultant scarring tends to seal up the pleural space, which prevents the re-accumulation of pleural fluid.



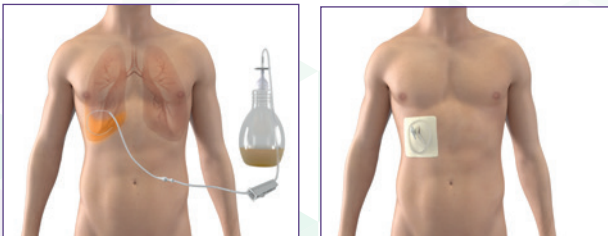
'I feel a lot better now that the fluid has been drained away'

Some patients might need an **Indwelling pleural drain (sometimes called a tunneled indwelling pleural catheter – TIPC)**

This is a permanent chest drain that is useful for recurrent pleural effusions when pleurodesis has not been successful or when the lung has become 'trapped' ie it does not fully expand when fluid is drained off.

The permanent drain has a small connection on the chest wall. When fluid accumulates a tube (pleural catheter) is inserted to which a drainage bottle is attached. Patients and their families can learn how to manage the drain themselves. Use of an indwelling pleural drain improves quality of life by reducing repeated painful drainage procedures in hospital and gives control back to the patient. Patients can even go swimming with an indwelling drain once it has been in for a while.

An indwelling drain might eventually allow a collapsed lung to re-expand and it can also create pleurodesis by enabling the two pleural layers to fuse together over time, thus leaving no space in which fluid can collect.



Figures 2 and 3: Indwelling pleural drain and chest wall site
Produced with permission of CareFusion

Surgery

Occasionally surgery is performed to relieve breathlessness. This might be because a) the lung has become fixed by the mesothelioma and is unable to expand or b) the mesothelioma has extended from the pleura into the lung and is reducing the volume of functioning lung. A pleural decortication (PD) procedure (debulking, Section 3) is conducted in these circumstances, provided that the patient is well enough to undergo the operation.

Things to do at home to relieve breathlessness:

a) Everyone who is breathless should try a *hand-held fan*

This is a very simple, cheap and safe tool that many people with breathlessness due to mesothelioma find extremely helpful. The small hand-held fan should be held about 8 inches (20 cms) away from the face, and the flow should be directed at the lower half of the face. Air should not be blown into the eyes as this causes dryness and irritation. The fan should be used whenever breathing gets difficult, continuing until the feeling improves. It is helpful to have several fans, keeping one in a pocket and others in the bedroom and car.

Small hand-held fans are preferred to large static fans because they promote a sense of mastery (ie control) and, being small and easily portable, can improve the patient's mobility. For patients who cannot tolerate a fan it might be helpful to use a flannel moistened with cold water and applied to the face when breathless.

For a demonstration of how to use a fan go to the following YouTube link: www.youtube.com/watch?v=y5tBC5R8DYs



Figure 4: Hand-held battery-operated fan

Hand-held fans can be obtained free of charge to patients from the June Hancock Mesothelioma Research Fund. See www.junehancockfund.org

b) Rehabilitation in breathlessness

Patients often restrict their activities because they know that moving around increases their breathlessness. Unfortunately this leads to a vicious circle whereby their inactivity causes muscle wasting and then it takes even more effort to move around – this is called deconditioning. It is important for patients and their families to understand that it is vital to move around as much as possible, within reasonable limits, and that gradually increasing activity over time will be beneficial and not harmful to the patient. This is particularly important in the early stages of the illness in order to preserve mobility and independence for as long as possible. Physiotherapists run pulmonary rehabilitation sessions and the GP can refer patients to them. Simple breathing exercises can reduce stress and muscle tension.

There are many different types of exercise designed to reduce the sensation of breathlessness and these are included in pulmonary rehabilitation programmes. People who are breathless tend to get very anxious and concentrate on breathing **in**. It can be very helpful for people to concentrate on breathing **out** instead, as in this pursed lips breathing technique:

Pursed lips breathing is a simple technique that can easily be performed at home:

Patients should breathe in through their nose whilst keeping their lips pressed together tightly, taking a normal breath and then breathe it out slowly through the centre of the mouth, taking about twice as long to breathe out as to breathe in. After repeating this several times the breathing should gradually come under control. (It might take a bit of practice to learn this technique.)

c) Complementary and creative therapies

Some people with breathlessness will find complementary therapies useful particularly anxiety is a significant factor. Various techniques such as relaxation, visualisation or hypnosis might be helpful. Referral is usually by the GP or specialist nurse (some hospices accept direct requests for assistance from patients and families). Local cancer charities or hospices usually provide these services free of charge.



d) Helpful positions when breathless



1. Lean forward with arms resting on knees when seated
2. Support the upper body on pillows on a small table in front of a chair when seated. A large V-shaped pillow can be helpful in a chair or as a prop in bed.
3. When standing, lean over a small table.

Figure 5: Helpful positions when breathless
(Picture source: <https://my.clevelandclinic.org>)

e) Consider using walking aids

Although it might be felt to be embarrassing, the use of a walking stick or other aid such as a wheeled trolley or frame will reduce effort and breathlessness when walking. Some people prefer to use lightweight walking poles such as those used by hill walkers.

f) Strong painkillers such as morphine

There is good evidence for using low-dose morphine and related drugs to relieve the sensation of breathlessness. This is an additional use for morphine alongside its usual pain-relieving role. In this situation patients can be reassured that there is no risk of becoming addicted or dependent on morphine when it is prescribed according to normal guidelines. If morphine is prescribed it will be helpful to always keep a supply on hand, including when out of the house or travelling.

g) Air or oxygen

Most people will find that a flow of cool air from a fan will relieve their breathlessness. Occasionally, if oxygen levels are reduced (demonstrated by a small device called an oximeter), oxygen will be prescribed. It can be supplied from a cylinder or, if needed for several hours in a day, from a concentrator. Oxygen is piped from the concentrator into rooms used by the ill person. Small portable oxygen cylinders can be carried in a backpack when outside the house eg to attend a social function.

h) Psychological therapies and benzodiazepines

Breathlessness creates anxiety and this unfortunately increases the distress associated with difficulty in breathing. A vicious circle can develop and so it is helpful to learn techniques for controlling anxiety. Simple things such as sitting in a comfortable armchair and listening to favourite music might be sufficient to help a patient regain control and to breathe more easily. Relaxation therapies are provided by a variety of organisations, the GP or specialist nurse can advise about local services (see b) and c) above). Medication such as benzodiazepines (a group of relaxants eg diazepam) can be useful to help with breathlessness if the patient is anxious or has difficulty sleeping but many of them are not suitable for long-term use.

i) Carer support

It helps enormously if family carers know how to assist when someone is breathless – both the ill person and the carer feel more in control and less distressed. Instead of watching and feeling helpless the carer can help to get the breathless person into a comfortable position, supply the hand-held fan, administer any medication that has been prescribed and prompt the patient to use relaxation techniques. It might be helpful to write down all the things that are useful in this situation.

If breathlessness is a serious problem, what to do in a crisis should be discussed with the GP or specialist nurse. If the breathlessness is severe, for example if the patient is unable to talk in sentences, or if there is a sudden deterioration in breathing, then the carer might need to call the GP or emergency services.

j) Treat other medical conditions

If the person with mesothelioma is on regular treatment for other medical conditions it is important to discuss **all** his/her medication with the GP. Some medications will need to be continued, eg if they help with breathing, whereas others might be no longer necessary. Pharmacists can also help with reviewing medications – this is called a ‘Medicines Use Review.’

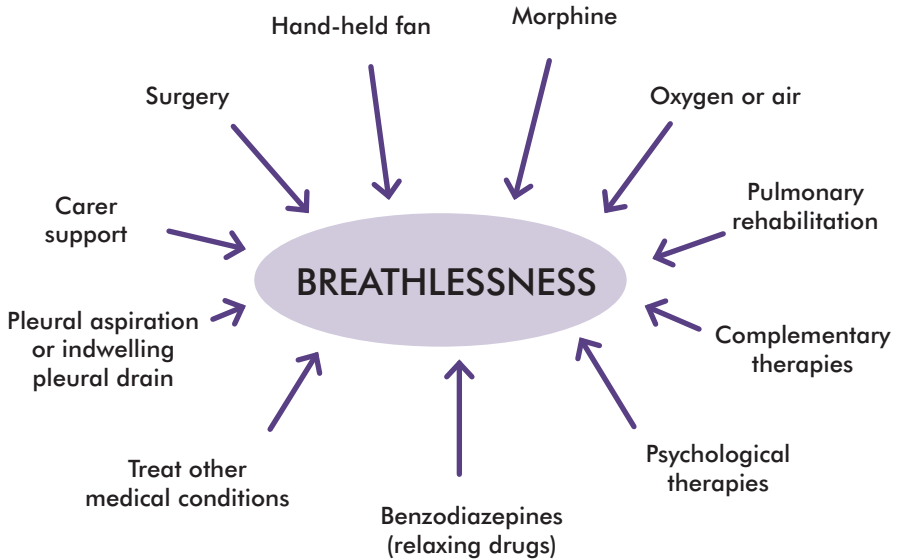


Figure 6: Multiple interventions for breathlessness (as described above)

Summary

In this section many different helpful interventions for breathlessness have been described. Most people will learn a few things that they can do at home to help themselves in addition to any medical treatments that are required. It is useful to find out what works for each individual as this builds confidence and reduces anxiety associated with breathlessness. It reassures family carers if they know what to do to assist someone who is feeling breathless. They can make sure a fan is available, help get the patient into a comfortable position and give low dose morphine or other medications. (A small proportion of patients will not experience any breathlessness).

A useful resource is the DVD produced by Clydeside Action on Asbestos, available online: www.clydesideactiononasbestos.org.uk/information-for-those-affected

Chapters 3,4,and 5 in this DVD cover managing breathlessness, gentle exercise, and stress and anxiety.

Pain in mesothelioma

Pain in mesothelioma can have several causes and that explains why it is sometimes difficult to find the correct treatment. The tumour can affect nerve tissues and the resulting 'nerve pain' might need unusual painkillers, for example some anti-epileptic drugs or antidepressants have particular qualities that make them effective in reducing nerve pain. It is often necessary to use these nerve pain drugs in addition to the conventional medications such as codeine or morphine. Patients often don't want to make a fuss and try to make light of their pain. However, if pain continues to be a problem after trying different medications the GP or specialist should be asked to refer the patient to a palliative medicine or pain specialist.

Painkillers should be taken regularly in order to be most effective. Sometimes patients experience episodes of pain that develop between the regular doses of painkiller. This is known as "breakthrough pain". It is helpful to ask the doctor to prescribe a fast-acting additional painkiller to use in this situation - this is often liquid morphine. If the patient experiences 'breakthrough pain' several times a day it might indicate a need for an increase in the dose of the regular long-acting painkiller, and this should be discussed with the doctor.



'It 's much better now that I'm on the new medication...'

Pain following surgery

Pleural decortication (PD), extrapleural pneumonectomy (EPP), and pleural biopsy can all cause pain around the incision in the chest wall. In particular, EPP can cause severe pain because there will be a large surgical incision and the pleura, lung, diaphragm and pericardium are removed. Surgery affects the rich nerve supply to these structures. If pain is not controlled quickly, patients should ask for referral to a palliative medicine or pain specialist.



a) Morphine and similar drugs

People tend to worry about taking morphine but it is an extremely effective painkiller and, when taken as prescribed for serious pain, will not cause problems with addiction or dependency. It is normally started at a low dose that is gradually increased if necessary until the pain is controlled. The most common side effect is constipation and therefore a laxative is normally prescribed with the morphine.

There are various types of morphine-like drugs (opioids) that differ in the way in which they are administered (eg liquid, tablets, capsules, patches, injections) and in their side effects. If side effects are a problem switching to a different opioid can be helpful.

b) Nerve pain drugs, nerve blocks and cordotomy

Mesothelioma often affects nerves in the pleura and rib cage. Nerve pain is often described as a burning sensation or 'electric shocks'. It sometimes makes the skin in the affected area extremely sensitive to touch (this can be very upsetting for relatives who want to put their arms around and hold someone who is obviously in pain). Nerve pain can require additional medication alongside opioids; some medications for nerve pain are commonly used as anticonvulsants (for epilepsy) or antidepressants.

Occasionally, if the pain is coming from one particular nerve that is affected by the mesothelioma, a procedure called a nerve block might be possible. This involves an injection or laser treatment that destroys the nerve.

Even less frequently a procedure called percutaneous cervical cordotomy is performed. It is used when there is pain that is difficult to control by the usual treatments and if the pain is on one side of the chest. Cordotomy involves an injection into the side of the neck to destroy the nerve fibres in the spinal cord that convey pain messages to the brain. This procedure is only available at a few specialised centres in the UK.

c) Anti-cancer treatments and radiotherapy

There is some evidence that the standard chemotherapy can reduce the main symptoms in mesothelioma although its prime purpose is to slow down the growth of the tumour. Radiotherapy is particularly useful if painful lumps develop on the chest wall. These usually arise from mesothelioma extending along the tracks made by insertion of surgical instruments and chest drains. There is now some evidence from a small clinical trial suggesting that low-dose radiotherapy can be effective in reducing chest pain due to mesothelioma. This is going to be investigated further in larger clinical trials.

d) Other painkillers

A variety of other painkillers can be helpful eg anti-inflammatory drugs (usually with a stomach protecting medication as they can irritate the stomach) or, if pain affects only a small area, adhesive patches containing local anaesthetic.

e) Psychological therapies

Pain and anxiety form a vicious circle. Pain is always worse if the person is anxious and anxiety is increased if pain is severe. It is helpful to find ways to reduce anxiety alongside using painkillers. Simple things such as relaxation sessions (for patients and/or family carers) can be arranged via the GP or specialist nurse.

A sense of control over pain is a great help. This can be achieved when the patient and the family carer learn 1) which medications work best for the pain and when and how to use them, and 2) what other sorts of activities reduce tension and help to ease the pain. Examples of these activities are: listening to favourite music, going for a gentle stroll, looking at photographs, picking up the phone to chat with an old friend, getting absorbed in a hobby or reading. Every person is different and needs to find his or her most helpful way of easing the pain.



f) Carer support

The family carer has a lot of new tasks and responsibilities when looking after someone with serious illness and it is vital that the healthcare team supports the carer. It is helpful to find one person amongst the many nurses and doctors who are involved in the care of each patient with whom a particularly good relationship can be developed, and to have a reliable method of contacting this person.

The carer might need to take charge of medication, particularly when it includes a number of different items. It might feel daunting to be responsible for strong painkillers such as morphine. In this situation the carer needs to know what each medication is for and when it should be taken, keep an up-to-date list, ensure that the patient does not run out of any medication and know how to contact the GP or pharmacy 24/7. It will help to talk to the GP or specialist nurse to understand the medications.

All medications must be kept safely out of the way of others, particularly children. Some modern preparations of the most powerful painkillers, such as lozenges or lollipops, might look particularly attractive to children, and accidental use by youngsters could be fatal. Urgent medical attention is essential if this occurs. Prevention of such emergencies is vital.

Patients should always keep an up to date written list of all medications, their doses, and the reasons for taking them.



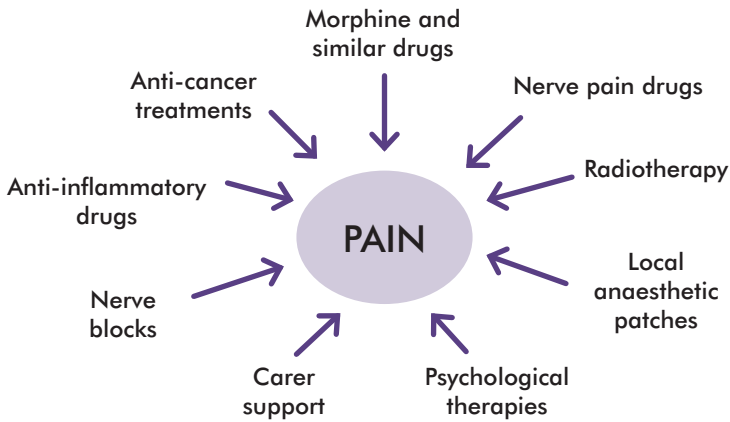


Figure 7: Multiple approaches to consider in pain relief

Summary

In this Section a variety of approaches to managing pain has been described. In most cases pain is controlled with medication and specialist procedures are only necessary in a small number. However, anyone who feels that pain is not well-controlled should ask the GP or specialist nurse for a referral to palliative care or to a pain management team. It is always better for patients, and in fact easier, to control pain before it becomes severe and persistent so no-one should hesitate to ask for specialist advice. (However, some patients might not experience any pain).



Other common physical symptoms

Nausea, weight loss and anorexia (loss of appetite)

These problems can be due to the illness or the treatments, eg chemotherapy, or a combination of both. It can be necessary to try several dietary adjustments and/or medications to find out what is best for each person - there is no single drug that will work in all cases. Taste often changes during the illness and people might find that they prefer to eat sweet things more than they used to, they might lose their liking for red meat and sometimes for alcohol too. Patients might also become very sensitive to odours such as perfumes or cooking aromas to the extent that these cause nausea and interfere with appetite. Cold foods might be preferred or it might help to change cooking methods to those that produce less smell, for example boil, steam or casserole rather than fry or grill.

This situation often creates tension in the household as the family carer tries to feed up the ill person – the idea of nurturing an ill person is common amongst family carers. However, piling food on the plate or constant reminders about food only make matters worse. The food that is prepared for the ill person needs to be adjusted to take into account the altered food preferences. Small portions are much more likely to be eaten than a plateful and using a smaller plate might make the food quantity appear more manageable.

If the person with mesothelioma is losing weight it is often necessary to forget all the advice about ‘healthy eating’ and make an effort to increase the calories in each meal by boosting with high-calorie ingredients such as butter, cream, ice cream, and chocolate, if the ill person can tolerate them. In some cases doctors might prescribe liquid nutritional supplements or meal substitutes but these are not always to the liking of the patient and there is little evidence to support their use in this situation. Home-cooked high-calorie food in small portions will usually be preferred. A hospital dietitian will provide advice if this becomes a major problem. Occasionally steroids are prescribed in the short-term to increase appetite.

Nausea will interfere with eating and might require more than one medication to control it. A home remedy worth trying is ginger in any palatable form. Acupuncture might help to stimulate appetite and reduce nausea; patients might prefer this approach, particularly if they are already on a lot of medication.

Sweating

Patients who suffer from excessive sweating should wear loose cotton clothing, use light cotton bedding and keep the bedroom cool. A fan or open window might be helpful. Hot or spicy food, hot drinks and alcohol and some medications can cause sweating. Pacing activities and avoiding rushing might help to reduce the problem.

Having a fine cold water mist spray, cold wet flannel or wet wipes, a dry tea towel (less bulky to carry around than a normal towel) or a refreshing cologne spray (if tolerated) available at all times is reassuring, and talc can prevent chafing. ‘Driclor’ is a powerful antiperspirant that is available on prescription and on sale in pharmacies.



In a rare situation sweating occurs just on one side of the body – usually affecting the head, neck and chest. This is due to particular nerves (of the ‘sympathetic’ or ‘involuntary’ system) being affected by the mesothelioma on one side only. It is called the ‘Harlequin syndrome’. This condition is annoying but not dangerous and needs managing as above. In a very few cases it might be treated by a special nerve block (stellate ganglion block).

Cough

If cough is persistent and not responding to simple measures or GP treatment, it should be investigated by x-ray or scan to see if there is a treatable cause. Sometimes a dry cough develops following radiotherapy but it usually stops after a week or two.

A simple technique to prevent dry cough:

The patient should sip water or chew a sweet when he/she feels the urge to cough. Alternatively the patient might find that a dry swallow is effective. This works because the brain cannot organise these two things, coughing and swallowing, at the same time! Traditional cough sweets and linctus might also be soothing. Prescribed cough medicines include codeine or methadone linctus but they can cause side effects such as constipation and sedation.

If there is difficulty coughing up thick phlegm inhaling steam can help, as will using a technique known as ‘huffing’ out – a nurse will demonstrate this, as does this website: [https://www.ummchealth.com/health_care_services/lungs_and_breathing_\(pulmonary\)/adult/cystic_fibrosis/cystic_fibrosis_testing_and_care/huff_cough_technique/huff_cough_technique.aspx](https://www.ummchealth.com/health_care_services/lungs_and_breathing_(pulmonary)/adult/cystic_fibrosis/cystic_fibrosis_testing_and_care/huff_cough_technique/huff_cough_technique.aspx)

Simple homemade remedies might help:

Aromatic drinks 1) honey, lemon, hot water +/- whisky, 2) hot blackcurrant

Inhaling steam +/- eucalyptus or other aromatics if phlegm is sticky

A traditional Indian cough remedy: (not scientifically evidence-based but much-used)

Mix 1 tbsp. of honey with 2 tbsp. of water, then add 1/4 tsp. of cayenne pepper, 1/4 tsp. of ground ginger, and 1 tbsp. of apple cider vinegar. Take once a day for cough (avoid breathing in dry cayenne pepper as this is an irritant)

A traditional approach in Pakistan:

Liquorice is used as a common cough remedy. You might try liquorice sweets or boil up natural liquorice root in water to make an infusion.

Fatigue

This is a very common problem in most cancers and causes a lot of distress as it has a major impact on daily activities. Controlling your activities as below may reduce the problem:

Planning and pacing activities.

This means planning ahead so that each activity is followed by a rest before doing the next thing that requires energy. The patient should also slow down the speed at which things are done. It sometimes makes sense to think of the available energy as being in a container and to avoid using it all at once. Patients should plan when and where it is most important to use up some of the supply, taking rests between activities. Another strategy is to think that something that used to take 30 minutes might now need an hour or be done in two stages with a rest in between.

Precious energy should not be wasted on things that are really not important! Patients need to learn to ask "Is this really necessary?"

Steroids might be prescribed to increase energy levels in the short-term, eg if the patient needs to attend a function such as a family wedding. This medication is not a *long-term* option for fatigue.

NB Alcohol might interfere with some medications and increase tiredness.

Difficulty swallowing (Dysphagia)

This is often due to **thrush (candida) infection** in the gullet and mouth. It can show as white patches stuck onto the mouth lining and tongue. Treatment is with anti-thrush medication. Natural remedies include live natural yogurt but medication is likely to be more effective in this situation. A dry mouth promotes the development of thrush and so keeping up a good fluid intake is important. Sometimes difficulty swallowing is due to pressure on the gullet from mesothelioma inside the chest – a scan or barium swallow will determine if this is the case.

Constipation

This is **inevitable** once patients are taking morphine or similar painkillers; constipation is a known side-effect of these medications. Reduction in physical activity due to fatigue, reduced food and fluid intake, and deteriorating health all tend to slow down the normal bowel activity. Therefore maintaining a good fluid intake and keeping as active as possible are important in reducing the severity of constipation. A prescription for morphine or most other powerful painkillers is usually accompanied by a prescription for a laxative. **The laxative should be taken regularly** rather than waiting for a painful and difficult crisis.

Home remedies such as prunes or prune juice, figs, rhubarb, high-fibre fruit and vegetables, and cereals eg wheat bran are helpful, usually in addition to a laxative. Abdominal massage and the following simple exercise might also help: The patient lies on the bed with both knees bent so that the legs are drawn up toward the body, then he/



she slowly moves both knees together from side to side, keeping his/her upper body as still as possible.

Hair loss as a side effect of some chemotherapy drugs

The standard chemotherapy for mesothelioma, pemetrexed and cisplatin, does not usually cause any major hair loss although it might cause some hair thinning. However, some of the other chemotherapy drugs that are occasionally used as second-line treatments could cause significant hair loss. Patients will be advised about any possible side effects before commencing treatment. If, unfortunately, major hair loss occurs, wigs are supplied through the NHS. Some patients who are facing significant hair loss prefer to take control of the situation and have their head shaved at an early stage. In this way they can quickly obtain an attractive wig without having to endure the distress of gradual hair loss.



Managing multiple medications

Due to the variety of different symptoms that might affect a person with mesothelioma the medications often amount to a large number of capsules, tablets, liquids and maybe other forms such as patches or injections. These all need careful management and in many cases the family carer takes on this responsibility.

It is helpful to put regular medications into a pill organiser such as a 'dosette' box. In some cases pharmacies will supply medications already sorted into regular doses for various times of each day in blister packs. It is possible to have medications delivered to the home if collecting them is a problem. Medications that are taken 'as required' or are not in tablet or capsule form have to be managed separately.

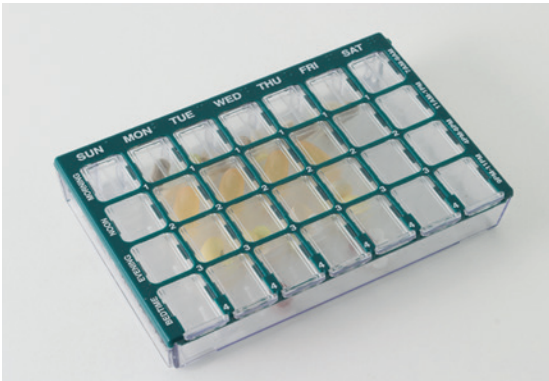


Figure 8: Example of a pill organiser for regular medications

Syringe drivers

In advanced disease, when the patient might find taking multiple medications burdensome, or if nausea and/or vomiting are a problem, the regular drugs can be administered in liquid form as a continuous infusion under the skin. This involves a fine 'butterfly' needle that is inserted under the skin and taped in place attached to a syringe containing the medication/s (usually sufficient for 24 hours) by thin tubing. The needle can stay in the same site for several days and is usually inserted under the skin of the upper arm but other sites such as the thigh or chest wall can be used. The syringe containing the medication/s is fixed into a small device called a syringe driver. The syringe driver slowly pushes the plunger into the syringe thus driving the medication/s down the tube and through the needle into the tissues just under the skin. The drugs are absorbed gradually into the rest of the body and this results in a very stable level of medication/s in the body. Patients usually find syringe drivers easy to tolerate. Occasionally there is irritation at the site where the needle is inserted but this can be relieved by changing the site or by using non-metal needles. District Nurses will replenish the syringe regularly and resite the needle if necessary.

Healthcare staff will discuss any potential side effects, such as sedation, with the patient (if possible) and/or family before commencing use of a syringe driver. The patient has the



right to refuse a syringe driver but in many cases use of a syringe driver is a very effective method for achieving good control of symptoms.

NB Keep the list of all the medications, including doses, and reasons for taking them, near to the syringe driver.



Symptom control

Mesothelioma is associated with multiple symptoms as shown in the table below. Most patients experience breathlessness and pain at some stage, to varying degrees.

Symptoms in pleural mesothelioma in the last year of life (Clayson H, 2007).

Breathlessness	96%	Social problems	16%
Pain	91%	Nausea (feeling sick)	14%
Cough	41%	Fatigue	13%
Weight loss	41%	Dysphagia (difficulty swallowing)	11%
Anxiety	31%	Psychiatric problems	10%
Anorexia (loss of appetite)	25%	Constipation	8%
Depression	19%	Ascites (fluid in the abdomen)	8%
Sweating	18%	Vomiting	5%
Emotional disturbance	16%	Painful metastasis (secondary cancers)	5%

It is not sufficient to apply lung cancer care to pleural mesothelioma because, although the incidence of breathlessness is about the same, pain is more common in mesothelioma than in lung cancer (see table below), and sleep disturbances and impairment of social role and functioning are also more common in mesothelioma (Nowak et al, 2004).

Comparison with lung cancer symptoms (Clayson H, 2007)

	Mesothelioma	Lung cancer
Breathlessness	96%	65%
Pain	91%	28-51%
Cough	41%	65-75%

Management of breathlessness

Most people with pleural mesothelioma will experience at least one episode of **pleural effusion**. **Pleurodesis** is performed in order to prevent recurrence and is most successful when performed early in the illness. If the mesothelioma has caused extensive thickening of the pleura, is encroaching into the lung resulting in reduced lung volume, or causing a fixed lung, then a **pleurectomy/decortication (PD)** procedure might be the preferred surgical option intended to restore the free movement of the lung and thus relieve breathlessness.

Other causes of breathlessness in mesothelioma

- Anxiety
- Coexisting illnesses, eg chronic obstructive pulmonary disease or heart failure
- Infection
- Anaemia
- Pericardial effusion (fluid around the heart) – NB medical emergency

Remember -

- Breathlessness can have multiple causes – not all are physical
- The sensation (or relief) of breathlessness does not correlate to blood gas, respiratory rate or oxygen saturation measurements
- **Therefore - the only reliable measurement is the self-reported experience of the individual patient.**

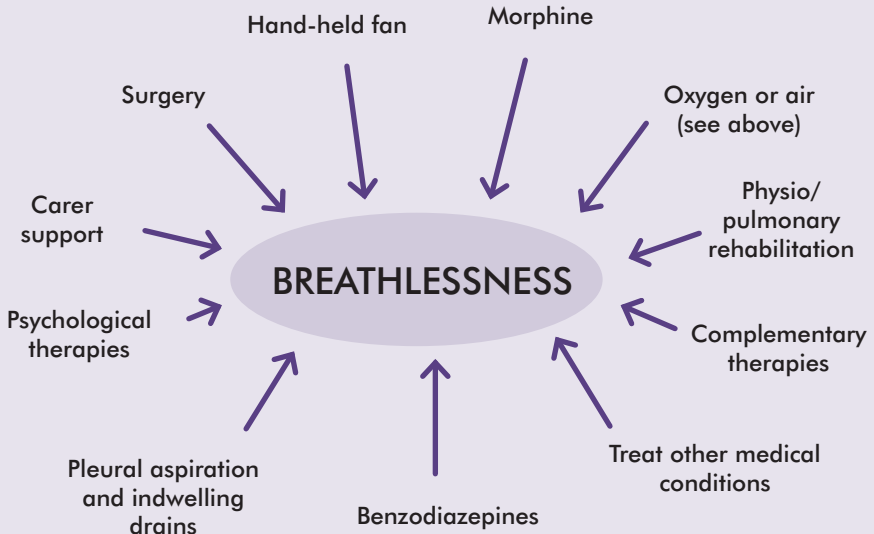
Alleviation of breathlessness

A multi-dimensional approach is essential to address the multi-factorial problem of breathlessness (see Figure 6).

Before breathlessness becomes refractory improve the patient's sense of mastery:

- explore the patient's understanding, hopes, fears and expectations
- involve family carers – they need to know how to help and when to call for assistance
- use rehabilitation if appropriate
- use oxygen if hypoxia is documented or if the patient finds oxygen better than a flow of cold air on the face - oxygen is difficult to stop once started and is a costly intervention

Figure 6: Multiple interventions for breathlessness



a) Hand-held fan

It is thought that the fan works because the flow of cold air causes stimulation of mechanical and/or temperature receptors associated with the trigeminal nerve in the face. This alters feedback to the brain, thus reducing the perception of breathlessness. The fan also promotes mastery.

For precise instructions about the correct way to use the fan refer patients to the following link if they have Internet access: www.youtube.com/watch?v=y5tBC5R8DYs

b) Rehabilitation in breathlessness

Refer to physiotherapy or occupational therapy for patients to learn some useful techniques for managing breathlessness.

c) Complementary and creative therapies

Often available through hospices and free of charge. Particularly useful when psychological factors are significant.

d) Helpful positions when breathless (see Figure 5, page 30)

Also consider aids and appliances to assist with daily living activities via referral to occupational therapy (eg V-shaped pillow, raiser/recliner chair, walking aids etc).

e) Indwelling pleural drain (Tunneled indwelling pleural catheter – TIPC)

This can greatly improve quality of life for people who have needed repeated admissions for aspiration of pleural effusions. The drainage can easily be done at home, by the patient or more usually by relatives if they are willing to be taught what to do. The drainage might need to be daily or less often. Over time the volume tends to reduce and in some cases, if the effusion is frequently drained completely, the pleural membranes might adhere together (pleurodesis). This obliterates the pleural space and so an effusion cannot accumulate and then the drain can be removed.

f) Morphine

The highest density of opioid receptors is found in alveoli, bronchi and trachea – this explains why opioids are effective. Morphine reduces minute ventilation by slowing respiratory rate and tidal volume. There is **no** evidence of respiratory depression when used in line with standard prescribing guidance for morphine and using no more than 30mg morphine per 24 hours.

It is standard practice to use 4-hourly oral liquid morphine initially, in order to establish the required daily dose. The total dose over 24 hours is then converted into a long-acting morphine, using a 12 or 24-hourly preparation in order to even out peaks and troughs.

Terminal dyspnoea (breathlessness), i.e. severe dyspnoea in the last stage of life

This is a rare situation and early management of breathlessness should usually prevent this developing. Intravenous morphine can be used: 2mg to 5mg IV every 5-10 minutes until relief. In rare cases where relief is not achieved with morphine, it is ethical and compassionate to provide sedation (eg intravenous benzodiazepine or barbiturate) either alone or with morphine in order to relieve severe distress. Teams, including palliative care, rather than practitioners working alone, should make treatment decisions in this situation. Sensitive communication with the patient, if possible, and with family members is essential in these circumstances. Advance care directives, if available, must be respected.

NB Refer to standard texts eg British National Formulary or Symptom Management in Advanced Cancer by Robert Twycross for more details or www.palliativedrugs.com

Managing pain in mesothelioma

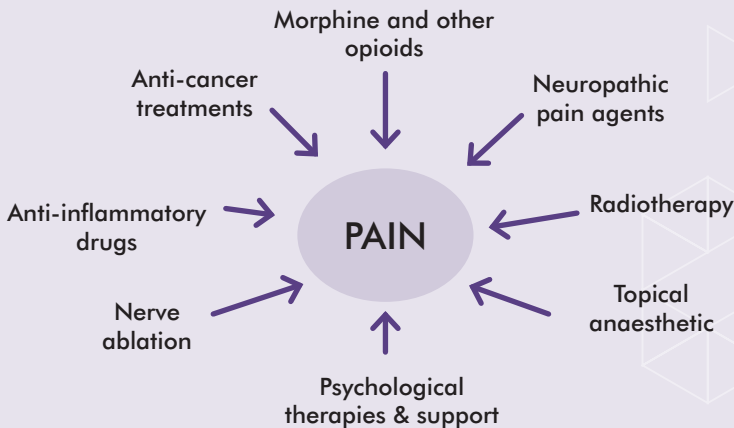
Pain in mesothelioma is frequently complex. It can be of inflammatory, tissue damage, damaged nerve, or bony origin – or a combination of any or all of these. Pain is classified as nociceptive pain (i.e. from tissue damage) or neuropathic (i.e. from damaged nerves). All types of pain can co-exist.

Nociceptive pain: The pleura, pericardial and peritoneal membranes exhibit an inflammatory response to asbestos fibres, and release chemical substances that cause inflammatory pain. Infiltration of ribs and vertebral bodies causes pain due to damaged tissue.

Neuropathic pain: This arises when mesothelioma either invades or compresses nervous tissues such as intercostal nerves, spinal nerve roots, brachial plexus, or, occasionally, the spinal cord. When the brachial plexus in the axilla is involved in mesothelioma the patient will experience severe neuropathic pain down the arm (and sometimes loss of function too); the distribution of pain will depend on which nerve roots are involved. Typical sensations: burning or coldness, raw, ‘electric shocks’, numbness, itching, tingling, hypersensitivity to stimuli (allodynia) and altered or uncomfortable sensations (dysaesthesia). It can be self-perpetuating. Patients typically rub or hold the affected area.

Psychosocial problems such as anxiety and/or depression will increase the perception of pain. Apart from using a variety of medications and/or interventions to control physical pain, the psychosocial issues affecting the patient and his or her family should be addressed. A multi-dimensional approach is essential.

Figure 7: Multiple approaches to consider in pain relief



Using morphine for pain

Refer to expert texts, examples below:

www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/choosing-and-changing-opioids.aspx

Titrate the dose to the symptoms:

Start low dose (2.5mg to 5mg) every 4 hours, using liquid oral morphine.

Increase slowly until pain is controlled. Then convert the effective total 24-hour dose to a sustained release preparation eg 12 or 24-hour preparation.

Always prescribe a breakthrough dose:

All patients who are prescribed sustained release morphine should have a supply of liquid oral morphine to use if breakthrough pain occurs. The standard breakthrough dose is equivalent to 1/10th to 1/6th of the total 24-hour dose.

Example: A patient who is taking slow release morphine 60mg twice a day i.e.120mg per 24 hours, should also have a supply of liquid oral morphine and take 12mg to 20mg (i.e. 1/10th to 1/6th of 120mg) if breakthrough pain occurs.

If a patient usually requires 3 or more breakthrough doses per day it is necessary to increase the long-acting dose accordingly and to recalculate the breakthrough dose as above.

If in any doubt about morphine (or other opioid) dosage check with the local palliative care team.

Always prescribe a laxative:

Constipation is inevitable – a combination of a prokinetic and an osmotic laxative is most helpful.

If opioid side effects occur consider:

- Is the dose too high?
- Would an alternative opioid be better?
- Ask 'Is this neuropathic pain?' If so, think about medication for neuropathic pain (see below) and, if prescribed, consider if the opioid dose should be reduced

If there are side effects or problems with the route of administration it may be preferable to use other opioids or formulations eg oxycodone or transdermal or transmucosal fentanyl. (Also consider methadone and ketamine – these two are for specialist use only). In terminal care, or if intractable nausea or vomiting occurs, continuous subcutaneous infusion of morphine +/- other required medications can be delivered via a syringe driver.

Information about compatibilities of multiple medications given in combination as a subcutaneous infusion can be found online: www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/syringe-pumps.aspx

Always be prepared to ask for advice if you are unsure. The local palliative care team will always be happy to assist you and it is sensible to involve them in the management of the patient if symptoms become difficult to control.

Management of neuropathic pain

Use antidepressants first-line eg amitriptyline
Consider adding an anticonvulsant eg gabapentin or valproate
NB Lidocaine (local anaesthetic) patches might relieve localised chest wall pain
If pain is not relieved consider referral for NMDA antagonists (e.g. methadone or ketamine which require specialist supervision) or other specialist interventions

Nerve blocks

Occasionally, if localised pain is difficult to control, a specialist in pain management might advise a nerve ablation procedure.

Delivering analgesia via spinal and intrathecal indwelling catheters are other options but managing these in the community might not be possible because they need expert attention.

Percutaneous cervical cordotomy

This involves ablation of the *contralateral* lateral spinothalamic tract (because nerves carrying pain signals cross over in the spinal cord) for unilateral severe chest pain occurring below the clavicle. Patients must be able to lie still for 1 hour and be conscious and able to cooperate. A needle is inserted into the neck just behind the ear, it is tested to ensure it is in the correct position; it is then heated up to destroy the nerve tissue. Patients are usually in hospital for 1 or 2 nights. Cordotomy is 'morphine-sparing' ie the dose of morphine or other opioids can usually be reduced significantly following a successful procedure. Complications (rare): paralysis of ipsilateral diaphragm, mild motor loss or dysaesthesia in the lower body. After some months alternative pain pathways might develop and cause dysaesthesia (an abnormal unpleasant sensation felt when touched). 80% achieve immediate benefit, 47% achieve prolonged benefit (Jackson et al, 1999). In around 1 in 20 patients the cordotomy cannot proceed due to technical difficulties and about the same proportion find the procedure difficult to tolerate. UK centres are in Liverpool, Oldham, Portsmouth and Warwick (Information sheet available from mesothelioma.uk@uhl-tr.nhs.uk).

NB In the author's experience this can be a useful option in a small proportion of people with severe pain due to pleural mesothelioma, but particular care should be taken with patients who have serious psychological distress. There is a risk that the procedure might be technically successful but the patient might get recurring pain as an example of 'total pain'. (Dame Cicely Saunders (1918 – 2005) introduced the concept of 'total pain' as the suffering that includes all a person's physical, psychological, social, spiritual, and practical difficulties).

A step-wise approach to mesothelioma pain

1. Use morphine or other opioid such as oxycodone if simple analgesics are ineffective and titrate the dose until pain is relieved (if side-effects cause problems switch to another opioid)
2. If symptoms suggest neuropathic pain change to or add a nerve pain agent eg amitriptyline
3. If pain is very localised eg to the chest wall, it might be relieved by lidocaine patches or, if it is due to a chest wall tumour, consider localised radiotherapy
4. If neuropathic pain continues consider switching to a different nerve pain agent or adding in a second medication
5. Pay attention to any psychological problems and offer support and/or treatment
6. If the pain is not rapidly controlled do not delay in referring to a pain specialist

A proactive approach is required

Do not underestimate the pain in mesothelioma: it is often severe and complex.

Do not delay. Be aware that in mesothelioma symptoms will tend to get worse, and so be prepared to adjust medication quickly.

Appropriate treatment by a specialist is frequently necessary. Pain in mesothelioma often requires high doses of opioids as well as of adjuvants. A multidisciplinary team approach is recommended. British Thoracic Society guidance (2007) recommends early referral to a palliative care specialist in mesothelioma. However, only ~50% UK patients with mesothelioma receive palliative care (National Lung Cancer Audit 2014 Mesothelioma Report).

Psychosocial support is vital. Psycho-emotional distress and anxiety pre- and post-diagnosis are common. The psychosocial issues exacerbate physical pain and contribute to 'total pain'.

Relatives need support and sufficient information to help them in managing the situation at home. This should include clear advice on when, who, and how to call for assistance.

Other common symptoms

Weight loss, anorexia (loss of appetite) and nausea

First-line medications are metoclopramide or haloperidol depending on the probable cause of the nausea/vomiting. If these do not work consider corticosteroid +/- levomepromazine. Nausea interferes with absorption, and vomiting is an absolute contraindication to oral medication, and so it is frequently necessary to deliver medication by an alternative to the oral route such as using opioid patches for pain relief or using a continuous subcutaneous infusion via a syringe driver. Many people with nausea/vomiting need a combination of several antiemetic medications for adequate symptom control. Advice on medication by subcutaneous infusion, including appropriate combinations in a single syringe, can be obtained from the local palliative care or

hospice team and from this website www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/syringe-pumps.aspx

Sweating

Medication: firstly check that sweating is not due to a high temperature or infection. Consider cimetidine, NSAIDS eg naproxen, or thalidomide (always with explanation).

Cough

Medication : consider cough suppressants eg codeine linctus, pholcodine, or morphine in advanced disease. Agents to loosen thick phlegm might be required eg carbocisteine (trade name Mucodyne).

Once treatable causes have been eliminated, consider dexamethasone, gabapentin, or fluoxetine, particularly if nerve irritation might be causing the cough.

Important: if refractory cough develops after surgery, rare post-operative complications should be considered eg bronchial fistula.

Fatigue

Treatable causes eg anaemia should be corrected if possible.

Consider referral, if not too ill, to physio, occupational therapy or breathlessness service for rehabilitation including advice on pacing or graded exercise programme.

Dysphagia (difficulty swallowing)

Candida infection is common and needs treatment with an antifungal such as fluconazole which is more effective than nystatin. A dry mouth will exacerbate problems and so artificial saliva might be required too. Sometimes difficulty swallowing is due to pressure from the mesothelioma on the oesophagus as it passes through the centre of the chest. A barium study or scan is required to investigate this and treatment depends on the exact nature of the problem. Occasionally a stent is inserted if there is severe narrowing of the oesophagus (a stent is a coil that keeps the oesophagus open).

Constipation

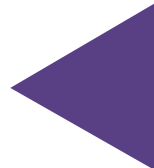
This is **inevitable** once patients are taking morphine or similar painkillers; constipation is a known side-effect of these medications. A combination of a stool softener with an osmotic or stimulant laxative is helpful. Ensuring adequate hydration is also important.

NB Always ensure that the patient and carers understand the essential preventative nature of a regular laxative and make sure that the medication is tolerated.





Psychological issues



Reactions to the diagnosis

Mesothelioma causes more psychological problems than most other cancers due to the nature of the illness, its causation by asbestos, and the complexity of the related civil compensation and State Benefits claims. Although not every patient is affected in this way, the following list covers some of the main issues that might contribute to psychological distress:

- Shock concerning the diagnosis and outlook
- Invasive and sometimes painful investigations and interventions
- Perceived lack of effective treatments
- Poor communication from healthcare staff, particularly bad communication of the diagnosis and outlook
- Lack of adequate support from healthcare services
- Isolation, feeling alone with this relatively uncommon illness
- Causation by asbestos and often self-blame (eg for taking risks at work)
- Concerns about possible asbestos contamination of family members
- 'Damocles syndrome' ie patients' sense of impending doom from knowing others who have died due to mesothelioma
- Difficult compensation claims and welfare benefits procedures
- Medical nihilism (negativity) which can sometimes be obvious
- Deteriorating health
- Facing death



'It helps to talk when I've got so many things on my mind...'



In many cases, once the initial shock of the diagnosis has lessened, patients become very determined to take one day at a time and to try to get the most out of life despite the illness. Relationships with family frequently become even closer and often patients and their family members talk of 'being in it together'. Inevitably, there are bound to be times of great sadness and awareness of loss, but mostly these are kept very private. Sometimes patients choose not to discuss the situation with anyone, including their closest relatives. This causes a lot of difficulties for relatives who need to understand their loved one's feelings in order to help him or her. Patients might prefer not to discuss their situation because they fear that it will cause emotional collapse for them or their relatives. Although an entirely understandable concern, this sort of reaction is very unusual and in the majority of cases patients and their families find things much easier once the situation can be discussed openly. Keeping feelings suppressed or having secrets within the family creates tension and isolation. This can also prevent the people affected making sensible decisions and plans for the future. It becomes very difficult for the healthcare team to understand the true situation when people are not being open and honest. However difficult it might be to discuss the situation there are many more advantages than disadvantages in doing so.

In some cases natural sadness develops into clinical depression. GPs and nurses will be on the alert for signs of this and will be keen to offer medication and/or counselling. One of the commonly used anti-depressants (mirtazapine) has the useful side effect of increasing appetite as well as lifting mood. Antidepressant drugs are not habit-forming and can be extremely effective, improvement in mood usually occurs in 2 to 3 weeks.

Anxiety is another common problem, often made worse by misconceptions and lack of information. Carefully delivered information, addressing the patient's fears, is key to relieving this condition. In many cases patients are reluctant to say what is really bothering them. Family carers need to try sensitively to discover what the patient's main concerns are. Complementary therapies offer a variety of approaches to relieving anxiety and many patients and their relatives find them helpful. Fitting the appropriate type of therapy to the individual person is part of the therapist's skill. Medication for anxiety might be helpful in the short-term but can sometimes have the unfortunate side effects of sedation, that is not helpful in people who are already prone to fatigue. It is sometimes helpful to face up to a range of future possibilities and try to take some control of the situation. A phrase that is often used to describe this is 'hope for the best but plan, just in case, for the worst'.

Anger is a common reaction experienced by people with mesothelioma and frequently relates to a former employer's negligence that allowed the workforce to be exposed to asbestos. It can also develop from an acknowledgement of ignoring risks many years ago, even when having been informed of the hazards of asbestos. There is often a sudden realisation that family members might have been put at risk from asbestos fibres brought home on work clothes. Anger might occasionally erupt (verbally) towards healthcare staff or family members, who need to understand how it has arisen and that it really is 'not personal'.

Anger experienced internally by the patient can lead to depression. Talking to others in the same situation, for example in an asbestos victims support group or on a mesothelioma help-line can be helpful. Understanding that others took the same risks and ignored advice about asbestos hazards in their youth might reduce feelings of guilt and self-blame.

Support for family members and other informal carers

Support means different things to different people. For some family carers simply having someone to talk to who understands their situation is most helpful. This support could be provided by nurses who are involved in the care or by a local asbestos victims support group, or on a telephone helpline such as that operated by Mesothelioma UK (see Resources Section 9).

Others might need support in terms of practical help with some of the physically demanding tasks such as transport to hospital appointments or with the increased washing and ironing if night sweats are a problem. **Carers should not hesitate to ask for more support** and should speak to their GP, District or specialist nurse about the things that are causing them particular difficulties.

'Carer collapse' affects both carer and patient and often results in hospitalisation of the patient, causing avoidable distress all round. Sometimes exhaustion from the emotional and physical demands of caring for a loved one with mesothelioma becomes overwhelming and carer and/or patient will desperately need a break. This should be discussed with the GP or District or Macmillan nurses.

Care at home will be easier if the carer is able to get a good night's sleep. Overnight sitters might be available through the local hospice or provided by Marie Curie. (See Resources section 9). Arranging a 'respite admission' before it becomes too difficult to continue care at home is sensible and avoids the risk of a serious crisis developing and an emergency admission to hospital. Most hospices offer 'respite admissions', usually of around 7-10 days. The surroundings are less hectic than in hospitals, specialised medical and nursing staff within a wider healthcare team care for the patient, and complex medication can be 'fine-tuned'. Hospices include care for the whole family in terms of listening to their needs, explaining the situation, and planning future care as well as providing supportive services eg relaxation therapies.

Family carers who are given good support will cope more easily with their demanding role and also tend to adjust better in bereavement.

It is important to emphasize that there can be very positive aspects to being a family carer. Many spouses report that, despite the sadness of the situation, they derive satisfaction and fulfillment from providing the best possible care for their loved one. A bereaved carer explained how she felt:

'I never felt of myself as a carer, I was his wife. I did everything possible to help him and he appreciated it. In fact, looking back, I would say it was a privilege, a real privilege, to look after him'.



Managing psycho-emotional problems

Depression

Standard assessment tools such as HADS (Hospital Anxiety and Depression Scale) or GHQ9 (General Health Questionnaire 9) are commonly used in order to establish the severity of anxiety and depression.

For depression consider antidepressants such as mirtazapine, which also stimulates appetite.

Some people might benefit from referral for counselling and brief psychological interventions might be appropriate in advanced illness.

Supporting carers

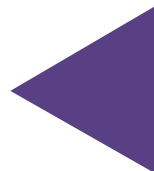
Carers' needs for support are often difficult to elicit – they tend to minimise their own needs and understandably prioritise the needs of the patients. Avoid asking carers 'Are you coping?' Acknowledge that people will be coping as well as they can and ask 'What sort of things can we help you to cope with?' or simply 'How can we help you to continue coping?'

Offer practical support such as overnight sitters, Marie Curie nurses, or hospice respite care to reduce the risk of 'carer collapse'.

Carers are legally entitled to an assessment of their needs. Carers' needs for support might be identified through a short questionnaire such as CSNAT (Carers Needs Assessment Tool) - obtain this online from www.ncbi.nlm.nih.gov/pubmed/23245452#



Communication about mesothelioma



Obtaining information

Patients and their families need and are entitled to compassionate and honest information about mesothelioma. However, a frequent comment from family carers is that they do not have adequate information about the condition, treatments and where to get support.

Relatives often need more information than patients and the type of information they need can differ too. Relatives need information in order to understand what is happening to their loved one, to deal with any problems that arise, and to try to plan ahead and be prepared for the inevitable progression of the illness.

It is very helpful for patients to always be accompanied by a close relative or friend (at the request of the patient) at consultations with healthcare staff. It is extremely difficult, especially when worried or feeling unwell, to remember everything that is discussed. The accompanying person can help by asking questions about issues that have caused concern or matters that need clarifying, and by making notes of the conversation for the patient and family to look at afterwards.

Confidentiality

All healthcare and social care staff are bound by their professional regulations to maintain strict confidentiality. This means that they must not discuss personal medical matters with anyone other than a patient (or his or her legal guardian or appointee) unless they have the permission of the patient to do so. Often this permission is implicitly assumed such as when a couple attend outpatient clinics together, or when there are discussions at home with husband and wife both present and clearly both are aware of the situation. However it is helpful if the patient clearly gives his or her permission for healthcare staff to talk to the nearest or preferred relative about the illness. This avoids any problems if the patient becomes too ill or does not want to talk about his or her condition.

The patient's permission for specified people to receive information about his or her condition should be clearly documented in the medical and nursing notes.





'Talking about it isn't easy....but it does help'

Coping

Patients and relatives are often determined to assure their healthcare professionals (and family and friends) that they are coping. This 'coping narrative' is an important strategy in mesothelioma. It restores a sense of control, bolsters self-esteem and stops questions and explanations concerning emotionally distressing areas. *BUT* it also gets in the way of asking for help and it can give a false impression, that everything is fine, to healthcare staff.

In order to achieve the best care for patients, family carers often have to be very specific about what they and the person with mesothelioma need. Family carers might need to 'spell it out' very clearly with friends and family, Many friends and relatives will genuinely want to help and are usually glad to be told a range of ways in which they could contribute. Things as simple as regularly walking the dog, mowing the lawn or doing the ironing can make a huge difference to an exhausted carer. Others might appreciate someone visiting regularly, providing transport to and from hospital, or simply being available for a telephone chat or a cup of tea. Getting to know others who are or have been in the same situation can be helpful eg through an asbestos victims support group. For people with mesothelioma who live alone it might be useful to draw up a rota of visitors and a list of tasks that they could help with. It might be necessary to spell out what is not needed too. For example, telling friends and family that you will be taking the phone off the hook if the patient is sleeping, or putting a note on the door saying 'Resting, please do not disturb' is better than being irritated or distracted by untimely callers. It can be simpler and quicker to send an update by group email regularly to family and friends rather than having the same telephone conversation many times.

Hospice at Home teams and the Marie Curie and Sue Ryder charities might be able to provide overnight or daytime respite care in which the carer gets some time to him or herself while a trained nurse or care assistant spends time with the patient at home. It does not matter if the carer does nothing special with this time, simply having a break from round the clock responsibility can be a huge help. Carers should not hesitate to ask the GP or nurses about this.

It should be recognised that not everyone is comfortable with taking on the care of a very ill loved one at home. Some people are just not suited to this role and to admit this and ask for help should not be seen as failure. Family carers who feel this way should make sure that the GP and community nurses understand their reservations and do not simply assume that care will readily be provided at home.. Sometimes, after finding out exactly what would be expected and the support available, some people might change their minds. However, a relative might be able to make a much more positive contribution through loving moral support and companionship whilst professionals provide all the healthcare.

See Section 9 for support groups, helplines and online discussion forum details – these can be a source of information and support for patients and/or carers.



Communication

Patients' wishes and permission regarding people they are happy to have receive medical information about their condition should be clearly documented in their notes and also communicated to out-of-hours services.

People with mesothelioma experience a high level of psycho-emotional distress. The severe burden of suffering relates to patients learning that they have a fatal illness, whilst undergoing unpleasant investigations and treatments, and they have additional worries relating to complex civil compensation and State Benefit claims. Although a few patients are long-term survivors, and some with early disease are treated actively with surgery, in many patients the disease progresses quickly and unfortunately most are unlikely to survive more than 18 months from diagnosis.

Learning the diagnosis and prognosis is a particularly difficult and shocking time for most patients and families. Kindness costs nothing; compassion and empathy from the professionals involved mean a great deal to people in this dreadful situation. Sometimes it might feel as if there is nothing useful that you can do, but simply 'being alongside' is a demonstration of your support and an acknowledgement of their suffering; this is generally much appreciated. If on the other hand the patient and/or family cannot bear to talk about any of their distress, and it is clear that they want to cope alone, you might need to accept the situation – but, from experience, this would be extremely rare. Of course their feelings might change over time and so patients and their family carers need to know that they can come back to you to talk things over if they wish.

Patients have a right to information about their condition. Information about diagnosis and prognosis that is necessary for the patient to make informed decisions about treatment should not be withheld unless it is judged that this knowledge would cause the patient 'serious harm' - being understandably upset is not the same as experiencing 'serious harm'. Patients might naturally be upset by knowing the truth about their condition but, in an advanced illness, they should have the opportunity to talk honestly with their family, to say good-bye to loved ones and to prepare for death. Although patients can be devastated by the diagnosis, most would prefer to know what is wrong rather than being misled and then worrying about why their health is deteriorating. Patients need full information in order to decide about treatment options and how they wish to spend the rest of their lives., Honest communication, however difficult, is essential and useful: it relieves tensions, restores a sense of control, it facilitates good end of life care, and improves the quality of relationships between family members, patients and their doctors and nurses.

Patients and families have reported how devastated and abandoned they feel if a doctor says, or gives the impression, that *'There is nothing we can do'*. Patients and relatives feel much stronger and supported if the doctor or nurse says something more positive, for example:

'I am sorry that your disease is not curable but there are many things we can do to try to slow the progress and to control symptoms. Whatever you choose for your treatment, we will respect your wishes and we will continue to support you and your family.'

Effective communication skills greatly help healthcare professionals to do their jobs well, reduce stress, and allow patients and their families to feel properly supported, even in the most difficult situations. Role play is extremely useful in learning about communication – it is as close as you might get to being 'in the patient's shoes'. Nurses might need to help rebuild a trusting relationship if communication has broken down with other healthcare professionals.

Coping

It is an essential role of nurses to assess the real situation. It is useful to acknowledge that patients and carers are indeed coping as well as they can, and to then ask

'What exactly are you having to cope with?' and

'What sort of support would help you to cope more easily?'

Mesothelioma frequently progresses quickly. The problems and symptoms often occur one on top of another in a short time and can feel overwhelming for patients and families (and sometimes for their doctors and nurses). It is distressing to have to deal with a new problem before solving the existing ones. This is what people with mesothelioma experience. In these complex situations it is helpful to ask patients what their priorities are and to follow their lead. Some of the problems cannot be solved but the patient and family will benefit from being able to rely on trusted professionals for support, compassion and sensitive but honest information.



The next few pages contain details about end-of-life care and procedures after death

Please read them when you feel
the time is right for you

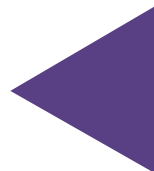
The information is very important and
so please do not ignore this section







Care in advanced disease



Preparing for the end of life

Talking with a loved one about the end of life is one of the hardest conversations to have. Although it is so difficult to raise this subject it is very important in mesothelioma because there are decisions and choices to be made if those who are ill are to receive the type of care that they want, in the place of their choice, with the people that they want to have with them. It can also be important to know what sorts of treatment the ill person might not wish to receive. In the NHS this is called Advance Care Planning. Only if these matters have been discussed can the ill person be confident that his or her wishes are known and understood and, likewise, only then can family carers be sure they know what their loved ones want. Our assumptions about another's wishes, in such a personal situation, are frequently wrong.

A family carer in a mesothelioma discussion group offered this advice:

'It's really important to be as honest as you can with each other...you might not get a second chance and then you might regret it later'

Dealing with these issues as early as possible is helpful. Once settled, these difficult matters can be 'put back in the cupboard' and everyone involved will understand the situation. It can be a comfort to know that you have acted in accordance with someone's wishes – and you won't know what they are unless there has been a discussion. Mesothelioma sometimes progresses very rapidly and then it might suddenly become too late for the discussions to be had. This can create a lot of practical and emotional difficulties for the families.

The GP and specialist nurses should be able to help with these conversations. Sometimes they will initiate the conversation because they also need to know what the patient wants in order to make an appropriate plan for his or her care. Occasionally it proves just too distressing for a person with mesothelioma to face these matters and this must be respected. However in most cases there is considerable relief when the subject is out in the open and everyone's worries have been addressed.

Relatives of people with terminal illness sometimes ask doctors not to tell the patient details of his or her condition, particularly if someone is deteriorating and approaching death. This is understandable, but doctors have a professional and moral duty to be honest with patients and so, without being unnecessarily distressing, should give honest answers to questions. Patients will usually have a sense of what is happening to them as they get weaker and there is no advantage in trying to hide the truth. Good relationships between patients and their doctors are based on trust. If the doctor knows what is most worrying the patient (eg is it fear of dying or how death will occur?) then he or she can talk about all that can be done towards achieving a dignified death. This subject might sound alarming to people reading it for the first time and yet we know, from experience,



that patients and/or carers need this information to work with healthcare professionals in planning the best possible care.

Some of the issues that patients might want to consider in thinking about their care in the weeks or days ahead are shown below. This list is not exhaustive, and anything else that is important to the patient can be added.

Advance care planning

Matters that patients might want to consider about end of life care:

- Where would you prefer to be cared for in the final stage of your illness? Stay at home or in hospital, hospice, nursing home?
- Who would you like to be with you?
- Who would you like to be consulted about your care eg family member?
- Who would you like to be informed about your condition eg family member/s or friend?
- Are there any treatments that you would not wish to receive? (For example resuscitation – the patient might want to discuss this with his or her healthcare team. A written instruction about treatment that a patient does not want to receive is called an Advance Directive to Refuse Treatment, sometimes referred to as a Living Will)
- Do you have strong feelings about continuing food and drink when close to death?
- What sort of religious, spiritual or other personal support would you like?
- Are there any particular issues concerning support needed for your close family?
- Are there any particular issues around care of your pets?
- If unfamiliar with the local hospice should you or a family member visit it to look round and meet the staff or ask a staff member to visit you at home?

Add any other issues that matter to you:

Discussions within families might also include such things as considering if there is any 'unfinished business' that patients would like to deal with eg mending broken relationships, or personal pleasures such as seeing old friends, visiting a special place, telling people how much they mean to them, leaving letters for special people...

Faith leaders will be very familiar with discussing issues related to the end of life. Some patients will want to be involved in planning their funeral, eg choosing readings and hymns or music that have special meaning for them.

As mentioned before, it is best to deal with these important things as soon as possible after diagnosis in case health deteriorates suddenly and then there might not be sufficient time or energy.

However, making end of life care decisions is entirely voluntary, and if people do not want to get involved in this, or find it simply too distressing, then they should not feel under any pressure to do so.

Practical matters

a) Organise the care

The patient's wishes and preferences are considered as part of what the NHS calls an 'Individual Care Plan'. Ideally these issues need to be clearly recorded in writing, the plan should be signed and dated and copies should be held by the healthcare team. For those who wish to use a standard form, the NHS has a document called Preferred Priorities for Care (often referred to as PPC for short). The GP or community nurses might have this form or it can be obtained online: www.macmillan.org.uk/Documents/Cancerinfo/ACPPreferredPrioritiesforCaredocument.pdf

There is no need to use this form as long as family and healthcare team know what the ill person does and does not want and it is written down. This Macmillan website also provides useful advice on advance care planning.

NB Making a written statement of the patient's wishes and preferences is the best way of ensuring that these personal choices are followed whenever possible. However, having a plan cannot guarantee that things will always go accordingly. Circumstances might change, things can alter suddenly, people can change their minds and in these situations the healthcare team will do whatever is necessary in the patient's best interest. Nevertheless, an Advance Directive to Refuse Treatment (a statement about treatment or care that the patient does not want) has to be adhered to. In the UK patients do not have the right to demand that they receive specific treatments.

b) Practical and financial matters also need sorting out eg making a will if this has not been done already, and ensuring that the spouse, partner or other appointee can access any bank or building society accounts etc.

c) It is helpful to consider appointing a close relative or friend as an attorney by making a Lasting Power of Attorney (LPA) (Health and Welfare). This means that, if a patient becomes unable to speak for him or her self, permission will have been given for the



person with Power of Attorney to speak/act on his or her behalf. Although it is possible to complete the application forms oneself it is much easier with help from a solicitor.

There are 2 types of LPA: 1. Health and welfare and 2. Property and financial affairs (see below)

Making a Lasting Power of Attorney

1. Health and welfare lasting power of attorney

This can only be used when you're unable to make your own decisions.

Use this LPA to give an attorney the power to make decisions about things like: your daily routine, eg washing, dressing, eating, medical care, moving into a care home, life-sustaining treatment

2. Property and financial affairs lasting power of attorney

It can be used as soon as it's registered, with your permission. Use this LPA to give an attorney the power to make decisions about money and property for you, for example: managing a bank or building society account, paying bills, collecting benefits or a pension, selling your home

You can choose to make one type or both. You can appoint one or more people as attorneys.

The registration fee is currently £110 for each type of LPA. Exemptions apply to people receiving certain means-tested benefits and 50% reduction for people on low income.

NB The system is different in Scotland and Northern Ireland – details are linked to the website below:

How to make a lasting power of attorney

- Choose your attorney (you can have more than one).
- Fill in the forms to appoint them as an attorney.
- Register your LPA with the Office of the Public Guardian (can take up to 10 weeks).

Make, register or end a lasting power of attorney - GOV.UK

<https://www.gov.uk/power-of-attorney/overview>

Contact the Office of the Public Guardian if you need help:

customerservices@publicguardian.gsi.gov.uk

Telephone: 0300 456 0300 Text phone: 0115 934 2778

Monday, Tuesday, Thursday, Friday, 9am to 5pm , Wednesday, 10am to 5pm

Helpful information about NHS provision of end-of-life care is available online:
www.nhs.uk/Planners/end-of-life-care/

Guides on planning ahead are available online from the National Council for Palliative Care:

www.ncpc.org.uk/sites/default/files/planning_for_your_future_updated_sept_2014%20%281%29.pdf

and from the Marie Curie charity

www.mariecurie.org.uk/help/terminal-illness/planning-ahead/preparing



Procedures after death

Information for family carers

This section is written on the advice of many former carers who have said how important it is that family carers need to know about these matters in advance, despite them being upsetting.

Most relatives report being treated sympathetically and with understanding in this distressing situation. It often comes as a shock to learn that the Coroner has to be informed whenever someone dies due to mesothelioma. This is because deaths due to mesothelioma are seen in law as 'unnatural'. According to UK law deaths that might be 'unnatural' have to be investigated by the Coroner in order to establish exactly why the person has died and which 'unnatural' cause was involved, such as asbestos in the case of mesothelioma. Even when there is a clear history of occupational asbestos exposure, and a firm diagnosis of mesothelioma, and no one has expressed doubt that mesothelioma has been the cause of death, the death must still be reported to the Coroner. He or she has a legal duty to conduct an investigation in order to establish the cause of death *in law*. This means that the doctor who attends the death cannot issue a death certificate and must, by law, inform the Coroner (or Procurator Fiscal in Scotland) of the death.

The Coroner's officer, often a police officer, will attend to take details about the deceased person, including the illness, details of work history and asbestos exposure. It is very helpful to have a written record of the work history of the person with mesothelioma. The record should include full details of time served as an apprentice, on work experience or in employment – with particular note of any contact with asbestos. (This record will also be essential for any civil compensation claim).

An inquest is opened (a formal process in Court) and is then adjourned while evidence is gathered. In many cases the Coroner will request a post mortem examination to be conducted. The body is usually released after the post mortem examination to the funeral director chosen by the family; this delays funeral arrangements by a few days in most cases.

Once all the evidence has been gathered the inquest will proceed and close family relatives are expected to attend and might have to give evidence to the inquest. The Coroner's officer and solicitor will explain the procedure in advance. The process is designed to establish the cause of death when death is thought to be due to an unnatural cause. It is important to recognise that the family members are not on trial and have certainly not done anything wrong. Their role is to assist the Coroner by providing information as to employment history or details of when the diagnosis was made, for example. Although it can seem a daunting experience, family carers should remember there is no suggestion they have done anything wrong and they are certainly not on trial.

Care in advanced disease

The document 'One chance to get it right' produced by the Leadership Alliance for the Care of Dying People in 2014 sets out recommendations that are intended to improve the care of people who are dying and their families:

'One chance to get it right' sets out 5 priorities for care of the dying, replacing the Liverpool Care Pathway:

- 1) The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly by doctors and nurses.
- 2) Sensitive communication takes place between staff and the person who is dying and those important to them.
- 3) The dying person, and those identified as important to them, are involved in decisions about treatment and care.
- 4) The people important to the dying person are listened to and their needs are respected.
- 5) Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

The document is available online: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Advance Care Planning

Advance Care Planning (ACP) is a voluntary process of discussion about future care between a patient and his or her healthcare providers.

The Gold Standards Framework has an excellent section on how to approach and develop ACP with patients, available online from www.goldstandardsframework.org.uk/advance-care-planning

There is valuable guidance on the General Medical Council website (www.gmc.org.uk), some of which is reproduced below, in italics:

End of life care: The benefits

50. As treatment and care towards the end of life are delivered by multi-disciplinary teams often working across local health, social care and voluntary sector services, you must plan ahead as much as possible to ensure timely access to safe, effective care and continuity in its delivery to meet the patient's needs.

51. The emotional distress and other pressures inherent in situations in which patients are approaching the end of their life sometimes lead to misunderstandings and conflict between doctors and patients and those close to them, or between members of the healthcare team. However, this can usually be avoided through early, sensitive discussion and planning about how best to manage the patient's care.

ACP discussions with the patient and family members if the patient wishes (or the patient's legal representative such as attorney) should cover the following

(a) the patient's wishes, preferences or fears in relation to their future treatment and care

(b) the feelings, beliefs or values that may be influencing the patient's preferences and decisions

(c) the family members, others close to the patient or any legal proxies that the patient would like to be involved in decisions about their care

(d) interventions which may be considered or undertaken in an emergency, such as cardiopulmonary resuscitation (CPR), when it may be helpful to make decisions in advance

(e) the patient's preferred place of care (and how this may affect the treatment options available)

(f) the patient's needs for religious, spiritual or other personal support.

Procedures after death

NB Make every effort to ensure that family members are aware of the Coroner's involvement before the death.

The doctor who attends the death has a legal duty to inform the Coroner of any death that might be due to mesothelioma. In order to avoid unnecessary confusion or distress at the time of the death, it is essential that the GP and out-of-hours services are made aware a) that the death is expected and b) that a Death Certificate cannot be issued and the Coroner must be informed. It may be necessary, particularly if an inexperienced police officer is covering for the Coroner's officer, to emphasise that although the death is technically 'unnatural' it is not 'unexpected'.

It is also essential to ensure that the family carers are informed *before the death* about the Coroner's involvement.

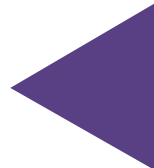
In some areas prior discussion with the Coroner about an anticipated death from mesothelioma might establish that he or she is happy for the death to be notified in normal working hours so that the regular (experienced) Coroner's officer will attend. In this situation ensure that out of hours services and community nurses are informed as well as the family that they can contact the Coroner during office hours.







Financial benefits and compensation claims



Every serious illness creates additional costs for patient and family, and there is a need to act in order to protect the financial security of the family. There are two routes to financial help in mesothelioma: 1) State Benefits and 2) pursuing a civil compensation claim against a previous employer (or their insurers) for negligence. This handbook provides an overview rather than a detailed account because these processes can be rather complex and subject to changes in regulations and law. This section gives details of organisations that can help.

State Benefits

People are often reluctant to claim State Benefits, but this is misguided. People with mesothelioma are entitled to claim various State benefits and they and their families will usually have contributed to this system. Illness is expensive, whether or not the ill person is in work, unemployed or retired, and the benefits go some way to covering the extra outgoings.

Everyone who has been diagnosed with mesothelioma is entitled to a lump sum payment from the state, this usually has to be claimed within a year of diagnosis. In the UK mesothelioma is recognised as a Prescribed Industrial Disease and as such attracts specific benefits, for example Industrial Injuries Disablement Benefit (IIDB), linked to past employment in which asbestos exposure occurred. The exact nature of these benefits depends on several things including whether or not the asbestos exposure occurred when the patient was an employee and what, if any, other benefits the household is receiving. *It is essential to get expert advice*, particularly if other benefits are received, because some benefits are linked to others and in some circumstances one benefit might interfere with another. People with mesothelioma are likely to be entitled to other benefits such as Personal Independence Payment (PIP) for under 65s and Attendance Allowance (AA) for over 65s. Asbestos Victim Support Groups provide advice and support in making claims for benefits. Mesothelioma UK and Macmillan Cancer Support provide advice by phone and online and in some areas can provide practical support with claims. Job Centres have benefits advisors and will supply the necessary forms. Family carers might be entitled to Carers Allowance in their own right. Contact details for the organisations mentioned above can be found in Section 9.

It is extremely useful to have expert help in completing the benefit application forms. This is usually provided by specialist nurses, benefits advisers attached to support groups, Job Centres and some solicitors. A medical certificate or letter from the GP or hospital specialist will be useful in confirming the diagnosis.

(NB it is a good idea to have several copies made of any certificates).

The DWP recognises the seriousness of the diagnosis of mesothelioma and does not normally require people with a diagnosis of mesothelioma to undergo any medical examinations.



Blue Badge

Patients should apply for a 'blue badge' either through the local authority or online through <https://www.gov.uk/apply-blue-badge>

A helpful website is www.disabilityrightsuk.org/blue-badge-scheme

Free prescriptions

Patients who do not already receive free prescriptions, should apply for an exemption on the basis of the diagnosis of mesothelioma. Medical exemption forms are available from GPs.

Aids and appliances

Equipment might be needed to make daily activities easier. Aids such as walking sticks, extra stair rail, perching stool, raised toilet seat, bed rails, pressure-relieving mattress, shower and bath seats etc can be provided free of charge. The District Nurse will usually suggest equipment that will help to avoid the ill person struggling and using up precious energy needlessly. An assessment regarding useful aids and appliances can also be conducted by an occupational therapist (OT).



'I think we should ring that helpline'

Making a claim for financial compensation

It is very important that, as early as possible, the claimant makes a record of his or her complete work history (including any apprenticeship, work experience or holiday jobs as a student) and of any known exposure to asbestos. This will form the basis of the claim.

The health hazards of asbestos were well known from the 1960s onwards but, although there were regulations then in place to protect the UK workforce, these regulations were frequently ignored. Employers who negligently exposed the workforce to asbestos that subsequently created health problems are expected to provide the injured worker with financial compensation. The employer's insurer usually covers this. If the firm has ceased and the insurer cannot be traced, a government scheme provides financial compensation, providing certain criteria are met. NB This does not apply to people who have always been self-employed although if they served an apprenticeship in which they were exposed to asbestos that might entitle them to claim compensation.

The legal process for asbestos-related claims is complicated and *it is essential that, in order to have the best chance of success, an expert lawyer is engaged*. There are many law firms advertising for this type of work ie Asbestos Related Personal Injury claims. However it is not necessarily the firm but the named expert solicitor who is important. Individual Asbestos Victims Support Groups and The Asbestos Victims Support Groups Forum UK (see Resources Section 9 for contact details) hold lists of solicitors that they have confidence in. Of course it is entirely the patient's decision which lawyer he or she chooses to appoint. Additional advice on civil compensation claims can be found in the Legal Advice section of the Mesothelioma UK charity's website: www.mesothelioma.uk.com and on the Macmillan website: www.macmillan.org.uk/Cancerinformation/Cancertypes/Mesothelioma/Livingwithmesothelioma/Financialhelpcompensation.aspx



How to decide on an expert solicitor – questions to ask

(From the Macmillan website)

1. Does the solicitor specialise in mesothelioma and asbestos-related lung cancer cases?
2. How many asbestos cases has the solicitor handled in the last three years?
3. How many of these have been dealt with at a court hearing?
4. Is the solicitor a Fellow of the Association of Personal Injury Lawyers (APIL)?
5. Will the solicitor provide you with a free initial consultation?
6. Will the solicitor visit you at home, if necessary?
7. Will the solicitor provide you with a free summary of what will be involved in making your claim?
8. Will the solicitor work on a 'no win, no fee' basis?
9. Will the solicitor obtain an insurance policy to cover legal fees?
10. Will the solicitor take a percentage of your compensation?
11. Will you be expected to pay expenses, such as medical report costs and court fees up front?
12. How will you be kept informed of what is happening with your claim?
13. How long will the claims process take?
14. How soon does the solicitor expect to start a court action?

Some people who have another asbestos-related condition such as pleural plaques will have already received compensation for that condition¹ as a 'full and final settlement'. Normally this means that a further claim cannot be made, even for a different illness, but there are some circumstances in which a new claim can be made. *Expert advice is required concerning this.*

If the patient has ever been a member of a trade union, even if it was many years ago, he or she might well be entitled to free legal advice from the union's legal assistance team. These teams hold extensive information about firms that exposed their employees to asbestos.

Under UK law, healthcare staff and support groups are expressly forbidden from referring patients and their families to a particular solicitor or from recommending a particular law firm, but they are able to provide lists of professionals that they trust to provide a good service. Patients are entirely free to choose from a list or to engage another solicitor of their choice. Many expert firms, especially those known to the support groups, do not charge claimants for these actions. Some lawyers will ask claimants to take out insurance to cover the cost of the case.

Statutory time limits apply to civil compensation claims: the claim must be made within 3 years from the date when the patient was told that he or she had mesothelioma. Claims can also be made by the family/dependents of the patient within 3 years of the death. In view of these limits it is important to commence the claims process as soon as possible after diagnosis. The person with mesothelioma will need to make a statement to a solicitor and that will include details of work history and employers, asbestos exposure and date of diagnosis of mesothelioma. Sometimes former work colleagues will be contacted for further information.

1. It has not been possible to pursue a claim for civil compensation for pleural plaques since 2007 in England but is possible in Scotland.

In certain circumstances, depending on the State Benefit/s received, once a civil compensation claim has been successful, the claimant will have to pay back all monies received in State Benefits. It is important to take expert advice in order to ensure that a successful claim would not be disadvantageous.

Medico-legal reports

In order to support a civil compensation claim the solicitor might request an independent medical report about the patient with mesothelioma. Any other health conditions will be taken into account in this report and the doctor writing it will make an assessment, based on statistics, of the life-shortening effect of the mesothelioma. The amount of any compensation awarded will relate to the estimated loss of expected years of life. Reports of this type have proved very disturbing when read by people with mesothelioma. There is no need for the patient or family to read the report, it has been written for the court.

One man with mesothelioma, who attended a discussion group to preview this handbook, told the group that he had been asked by his solicitor if he wanted to read the medico-legal report. He agreed, found the report to be extremely upsetting, and seriously regretted reading it. He described the information contained in the report as ‘very distressing’ and insisted that his wife did not read it.

Making a complaint about treatment or care

If things have not gone well and a patient feels that standards of care, treatment or communication have been poor, the appropriate person in each healthcare organisation should be contacted. It might be sufficient to speak to the person concerned directly, or alternatively to contact someone whose job includes handling complaints.

In some circumstances it might be sufficient to ask to see another doctor - every NHS patient has the right to request a second opinion and this can be arranged through a specialist or GP.

It is important to report any problems, as this should result in improved standards and avoid anyone else experiencing similar difficulties. Usually 3 years will be allowed from the date of ‘logging’ a complaint to having it acted upon. This means there is no need for anyone to get involved in the process whilst dealing with a serious illness (provided the complaint has been ‘logged’) as the matter can be returned to once there is more time.

In General Practice: contact the Practice Manager
In hospital: contact the Patient Advice and Liaison Service (PALS) or similar
In the community: contact the local Clinical Commissioning Group (CCG)
In hospice: contact the person in charge

Practical and detailed advice is available online: www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/AboutNHScomplaints.aspx

On the other hand, if care has been excellent, healthcare organisations are always very pleased to receive letters of appreciation.







Useful resources



These are resources that people affected by mesothelioma or healthcare professionals have found useful, it is not a comprehensive list.

Reliable information about mesothelioma:

Mesothelioma UK is a national mesothelioma charity that has an informative website and also runs a telephone helpline for patients, family carers and professionals. Mesothelioma UK raises funds for research into mesothelioma and holds an annual conference: Mesothelioma UK Patients' and Carers' Day. Mesothelioma UK provides education for nurses, and has developed the role of specialist mesothelioma nurses, 6 are currently in post across England.

Website: www.mesothelioma.uk.com

Freephone advice line 0800 169 2409 between 0830 and 1630, Monday- Friday
email: mesothelioma.uk@uhl.tr.nhs.uk

June Hancock Mesothelioma Research Fund is an independent UK charity dedicated to raising funds for mesothelioma research and for the care of people with mesothelioma. JHMRF was started in 1997 and has raised over £1.4m. The charity campaigns to raise awareness of mesothelioma and the risks of asbestos.

Website: www.junehancockfund.org

Telephone: 0114 274 4420

Mick Knighton Mesothelioma Research Fund is a Newcastle-upon-Tyne-based charity that is now part of the British Lung Foundation (BLF). MKMRF raises funds to support research into mesothelioma and also runs support groups in NE England.

Website: www.blf.org.uk

Telephone BLF Helpline: 03000 030 555 - lines are open Monday to Friday, 9am – 5pm

Asbestos Victims Support Groups Forum UK this is the umbrella body for most UK asbestos victims support groups and can provide details of the locations of the groups. The Forum supplies information on obtaining expert advice on State Benefits and can also suggest how to obtain expert legal advice regarding compensation claims. The Forum campaigns on behalf of people with asbestos-related diseases and has achieved significant changes in relevant law.

Email: asbestos.mcr@gmail.com

Website: www.asbestos-victims-support.org



Meso Warriors on Facebook

Mavis Nye set up this Facebook page when she was diagnosed with mesothelioma in 2009. Many people affected by asbestos, and their carers, contribute comments and information. Mavis pursues all available treatment options and continues to participate in clinical trials. She works within the NHS as a Patient and Trial Rep.

Read Mavis's story online:

www.asbestosjustice.co.uk/mavis-nyes-story/%20http://rayandmave.weebly.com/

Website: www.facebook.com/pages/Meso-Warrior

The International Ban Asbestos Secretariat (IBAS) is based in London and led by Laurie Kazan-Allen, campaigner and activist. IBAS produces a regular newsletter that reports on the international fight for justice for asbestos victims, and campaigns for a global asbestos ban.

Website: www.ibasecretariat.org

Services for cancer patients

Macmillan Cancer Support assists people affected by cancer by providing practical, medical and financial support and campaigning for better cancer care.

Website: www.macmillan.org.uk

Freephone advice line 0808 808 0000

Marie Curie (charity) provides a range of services to assist and support people who have advanced and terminal illness. Marie Curie nurses work in peoples' homes and in 9 Marie Curie hospices in the UK. Volunteers offer help with practical tasks, companionship and emotional support.

Website: www.mariecurie.org

Free confidential support and advice line on all aspects of terminal illness:
0800 090 2309

Sue Ryder (charity) provides end of life care in 7 inpatient hospices; doctors, nurses and other professionals in multi-disciplinary teams that support patients in their own homes; and community nurse specialists that work alongside GPs and their teams.

Website: www.sueryder.org

Telephone: 0845 050 1953

Email us at: info@sueryder.org

Hospice UK is the national charity for UK hospices. The website provides details of UK hospices and the services that they provide.

Website: www.hospiceuk.org

Cicely Saunders International is a charitable organisation dedicated to improving the care and treatment of all patients with progressive illness and to make high quality palliative care available to everyone who needs it.

Tel: 020 7848 5580

Email: info@cicelysaundersinternational.org

PatientOpinion is an online independent not-for-profit patient feedback forum where you can report your experiences (good or bad) of healthcare that will be fed back to NHS organisations.

Website: www.patientopinion.org.uk

Tel: 0114 281 6256

Advice on State Benefits is available from local Job Centres, Citizens Advice Bureaux and from the official website: www.gov.uk/browse/benefits

Mesothelioma Research Charities

There are many charities that raise funds for cancer in the UK but the following raise funds specifically for mesothelioma:

June Hancock Mesothelioma Research Fund is an independent UK charity dedicated to raising funds for mesothelioma research and for the care of people with mesothelioma. JHMRF was started in 1997 and has raised over £1.4m. The charity campaigns to raise awareness of mesothelioma and the risks of asbestos.

Website: www.junehancockfund.org

Telephone: 0114 274 4420

Mick Knighton Mesothelioma Research Fund is a Newcastle-upon-Tyne-based charity that is now part of the British Lung Foundation (BLF). MKMRF raises funds to support research into mesothelioma and also runs support groups in NE England.

Website: www.blf.org.uk

Telephone BLF Helpline: 03000 030 555 - lines are open Monday to Friday, 9am – 5pm

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Website: www.mesothelioma.uk.com

Freephone advice line: 0800 169 2409 between 0830 and 1630, Monday- Friday

email: mesothelioma.uk@uhl.tr.nhs.uk



Asbestos victims support groups

This list contains most of the support groups in the UK but it is not complete as new groups might start and others cease. Groups that are provided by firms of solicitors are excluded.

List of the main asbestos victims support groups in England

Asbestos Support West Midlands
138 Digbeth,
Birmingham B5 6DR

0121 678 8883
asbestosinfo@wmht.co.uk
www.asbestosupportwm.org

Bradford Asbestos Victims Support Group

Workers Health Advice Team
c/o Bradford Resource Centre
17-21 Chapel Street
Bradford, BD1 5DT

01274 393949
contact@what-bradford.org.uk
<http://what-bradford.org.uk/9.html>

Cheshire Asbestos Victims Support Group

3 Fryer Street
Runcorn, Cheshire WA7 1ND

01928 576641
cavsg@btconnect.com
www.cavsg.co.uk

Cumbria Asbestos-related Disease Support

c/o Barrow & District Disability Association,
71-77 School Street,
Barrow-in-Furness
Cumbria LA14 1EJ

01423 206 570
cardsadvice@gmail.com
www.cumbria-ards.co.uk

Derbyshire Asbestos Support Team

34 Glumangate
Chesterfield S40 1TX

01246 380415
mail@asbestosupport.co.uk
www.asbestosupport.co.uk

Greater Manchester Asbestos Victims Support Group

Windrush Millennium Centre, Unit 2.5
70 Alexandra Road, Moss Side
Manchester, M16 7WD

0161 636 7555
asbestos.gmavsg@gmail.com
www.asbestos-victims-support.org

Hampshire Asbestos Support & Awareness Group

79 Radstock Road
Southampton
Hampshire SO19 2HT

02380 010 015 and 02380 010 16
lisa@hasag.co.uk; lynne@hasag.co.uk
www.hasag.co.uk

Merseyside Asbestos Victims Support Group

3rd Floor, Oriol Chambers,
14 Water Street
Liverpool L2 8TD

0151 236 1895
info@asbestosdiseases.org.uk
www.asbestosdiseases.org.uk

South Yorkshire Asbestos Victim Support Group

SARAG
Unit 37
Moorgate Crofts Business Centre
South Grove
Rotherham S60 2DH

01709 360 672
sarag.asbestos@gmail.com
www.saragasbestosupport.org

Mick Knighton Mesothelioma Research Fund

c/o British Lung Foundation, Sir G B Hunter Memorial Hospital
The Green, Wallsend NE28 7PB.

0191 263 7386
cknighton-mkmrf@btconnect.com
www.mickknightonmesorf.org

List of the main asbestos victims support groups in Scotland

Asbestos Action Tayside (covering East of Scotland)

Asbestos Action Tayside
Caledonian House
Greenmarket
Dundee DD1 4QB

01382 225715
alison@asbestosactiontayside.org.uk
john@asbestosactiontayside.org.uk
www.asbestosactiontayside.org.uk

Clydebank Asbestos Group

8 Crown Avenue,
Radnor Park
Clydebank G8 3BW

0141 951 1008
clydebankasbestos@ntlbusiness.com
www.clydebankasbestos.org

Clydeside Action on Asbestos

245 High St, Glasgow G4 0QR

0141 552 8852
admin@clydesideaction.co.uk
www.clydesideactiononasbestos.org.uk

The asbestos victims support group in Wales

Asbestos Awareness & Support Cymru

02920 363550
enquiries@a-a-s-c.org.uk
www.a-a-s-c.org.uk

At the time of writing there does not appear to be any asbestos victims support group in Northern Ireland.

References for healthcare professionals

National guidance on treatment and care

NICE guidance: Pemetrexed in the treatment of mesothelioma
www.guidance.nice.org.uk/ta135

British Thoracic Society Statement on Mesothelioma (2007). A new BTS guideline for the investigation and management of mesothelioma is in preparation, with a likely publication date in 2016. www.brit-thoracic.org.uk/guidelines-and-quality-standards/mesothelioma/

Palliative care in mesothelioma

Abernethy A, Currow D et al. (2003) Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea *BMJ* 327(7414):523-528

Ahmedzai S A, Clayson H (2006) Palliative Care in Mesothelioma. In: O'Byrne K and Rusch V (eds) *Malignant Pleural Mesothelioma*. Oxford: Oxford University Press, 402-433

Cambridge Breathlessness Intervention Service Manual. Available online:
www.cuh.org.uk

Clayson H, Seymour J, Noble B. (2005) Mesothelioma from the Patient's Perspective. *Hematol Oncol Clin N Am* 19: 1175-1190

Clayson H (2007) Thesis: The Experience of Mesothelioma in Northern England. University of Sheffield. Available online at etheses.whiterose.ac.uk/1775/

Clydeside Action on Asbestos breathlessness self-management DVD available online:
www.clydesideactiononasbestos.org.uk/information-for-those-affected

Or by post, free of charge, from CAA, 245 High St, Glasgow G4 0QR
 TEL: 0141 552 8852

Chapters 3,4,and 5 cover managing breathlessness, gentle exercise, and stress and anxiety.

Jennings AL et al(2002) A systematic review of the opioids in the management of dyspnea. *Thorax* 57:939-44,

Nowak A, Stockler MR, Byrne MJ. Assessing quality of life during chemotherapy for pleural mesothelioma: feasibility, validity, and results of using the European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire and Lund Cancer Module. *Journal of Clinical Oncology* 2004; 22:3172-80.

Temel JS, Greer JA, Muzikansky A (2010) Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *N Engl J Med* 363:733-42. (not a mesothelioma study but useful and being studied now in mesothelioma in the RESPECT-Meso trail).

Twycross R, Wilcock A, Toller CS.(2009) Symptom management in advanced cancer. 4th edition (2009) Palliativedrugs.com Nottingham UK.

Relevant books

Malignant Pleural Mesothelioma. O'Byrne K and Rusch V (eds) Oxford: Oxford University Press, 2006.

Lethal Work: A History of the Asbestos Tragedy in Scotland by Ronald Johnston, Arthur J. McIvor (ISBN: 9781862321786) East Linton, Tuckwell Press, 2001.

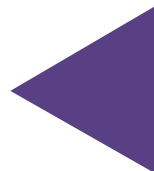
The Politics of Asbestos: Understandings of Risk, Disease and Protest (Pathways to Sustainability Series) Linda Walden (Print ISBN: 9781849711074, eBook ISBN: 9781849775670) Taylor and Francis Ltd, 2011.







Important telephone numbers



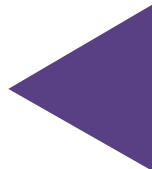
Contact	Telephone number	Notes
GP practice		
Out-of-hours GP		
Pharmacy		
District Nurse		
Out of hours District Nurse		
Specialist nurse		
Hospital		
Hospice		







Pages for your notes



It is helpful to note down the following:

- Employment history including time served as an apprentice or in the Armed Forces
- Significant dates eg date of diagnosis and all appointments
- Details of important consultations
- Any questions that you have

A series of horizontal dotted lines for writing notes, covering the majority of the page below the list.





Acknowledgements



The Handbook includes information suggested by many contributors. The majority of these have been people with mesothelioma, family carers of people with mesothelioma and healthcare professionals involved in treating and supporting people with mesothelioma. They have all generously given their time to read the drafts of the handbook and feed back comments based on their knowledge and experience.

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The inspiration for this Handbook was a small booklet for Japanese nurses about the care of people with mesothelioma, based on lectures I gave in Japan in 2012. It was written by Dr Yasuko Sarah Nagamatsu, Associate Professor, St Luke's International University, Tokyo. I am very grateful to Dr Nagamatsu for her initiative, friendship and support.

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The people listed below, in alphabetical order, have all contributed by previewing the Handbook in draft and providing many useful suggestions. The list includes people affected by mesothelioma: patients, carers, former carers, support group members, focus groups participants in Leeds and Manchester, legal and healthcare professionals.

Please accept an apology if anyone has inadvertently been omitted. Lindsay Bayles, Dr Sara Booth, Dr Isobel Clayson, Lorraine Creech, Eileen Curtis, Liz Darlison, Dr Greg Deleuil, Graham Dring, Carol Exley, John Flanagan, Heather Foot, Valerie Grieve, Dr Kate Hill, Marie Hughes, Avril Jackson, Doug Jewell, Laurie Kazan-Allen, Alan Lodge, Deidre McGerven, Dr Yasuko (Sarah) Nagamatsu, Professor Bill Noble, Mavis Nye, Ann Oldham, Carol Parfremment, Alan Parker, Robert Pointer, Margaret Poole, Vera Rigby, Mavis Robinson MBE, Dr Arthur Rose, Lauren Ross, Zoe Sandell, Malcolm Scoltock, Pauline Scoltock, Gary Shaw, Kimberley Stubbs, Mavis Tonge, Marian Wilson.

I hope that this Handbook has been useful.

Helen Clayson

March 2016

Feedback is welcome by email to handbook@junehancockfund.org



About the June Hancock Mesothelioma Research Fund

The June Hancock Mesothelioma Research Fund is a UK registered independent charity. Since we were set up in 1997, our supporters have raised well over £1.5m. The Fund is run by six volunteer trustees and we therefore have no staff costs or overheads.

The funds we raise are used to offer awards for research projects that aim to understand how mesothelioma develops and progresses in order to find new ways of tackling the disease and improve treatment and care for patients. We are a partner organisation of the National Institute of Health Research.

Our research portfolio has grown over the years and we fund a whole spectrum of projects from basic laboratory science studies to investigations concerning symptom control and palliative care. We also fund doctoral and training fellowships that have a sound research component, and we have developed successful partnerships with organisations that provide matched funding to support the fellowships.

In addition to our research activity, we campaign to raise awareness of the disease and the risks of asbestos. We also aim to support people with mesothelioma and their families, friends and carers by providing information. We do this in two ways: we provide funds to enable the local support group Mesothelioma Support Yorkshire to hold monthly meetings and we produce The Mesothelioma Handbook.

The original Mesothelioma Handbook was written by Mavis Robinson MBE; her commitment to improving care for people with mesothelioma was the foundation of the network of specialist nurses that exists today. The latest handbook replaces the second edition published in 2008, and is a worthy successor. The author, Dr Helen Clayson, is a long term advocate for mesothelioma patients.

For more information about the June Hancock Mesothelioma Research Fund please visit our website www.junehancockfund.org or email info@junehancockfund.org. We hope you will find the new handbook a valuable and helpful companion. Donations are always welcome to help us continue to fight mesothelioma with good science and high quality research, and to enable us to provide information and support.

Further copies of this Handbook can be obtained from The June Hancock Mesothelioma Research Fund.

Email a request to handbook@junehancockfund.org (patients might ask the GP or specialist nurse to email on their behalf).

Please remember to include your name, address and postcode.

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