

Mesothelioma

Information for people with **Mesothelioma** and their carers

Mesothelioma

Compiled by
Mavis Robinson MBE, RGN

2005
Edition

Introduction

This booklet is written in an attempt to give basic information and guidance on Mesothelioma.

The booklet is in three parts.

1 What is Mesothelioma?

This is about the disease itself and is written in a 'question and answer' format to answer the most common questions asked about mesothelioma. I'm sure there are many more which are beyond the scope of this small booklet, but further sources of information and advice are listed in part 3.

2 Financial & Legal

This is about the financial and legal aspects, Benefits, compensation claims etc. This is only a brief guide about what you may be entitled to and how you can get further help.

3 Helplines

This consists of national sources of help and information, useful telephone numbers and websites.

Mesothelioma

**What is
Mesothelioma?**

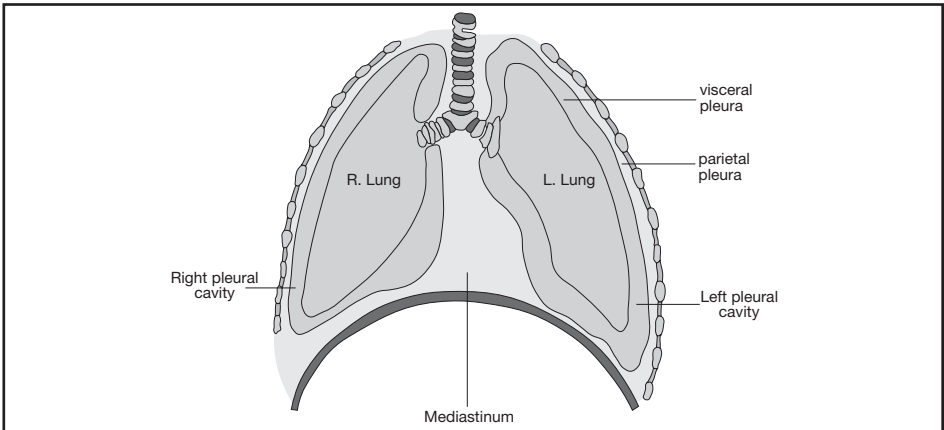
Mesothelioma

1

Mesothelioma

What is Mesothelioma?

Mesothelioma (also known as 'diffuse' or 'malignant' Mesothelioma) is a form of cancer, which affects the thin membranes which line the chest (pleural mesothelioma). Less commonly it can affect the linings of the abdomen (peritoneal mesothelioma). It may also surround the organs found within these cavities for example the heart, lung and intestines.



Pleural Mesothelioma

The pleural lining has two layers - an inner (visceral) layer which lines the lung and an outer (parietal) layer which lines the chest wall. The pleura produce fluid to lubricate the space between the two layers allowing the layers to slide comfortably over each other as we breathe.

Pleural Mesothelioma causes the pleura to thicken. This may make it press on the lung or attach itself to the chest wall. Fluid, sometimes several litres, can collect between the two layers and cause breathlessness. This is known as a **Pleural effusion**.

Peritoneal Mesothelioma

The peritoneum also has two layers, the inner (visceral) layer which is next to the abdominal organs and the outer (parietal) layer which lines the abdominal wall. Peritoneal Mesothelioma causes the peritoneum to thicken and fluid to collect in the abdomen, this collection of fluid is called **ascites** and causes the abdomen to swell. Peritoneal Mesothelioma is much less common than Pleural Mesothelioma.

Mesothelioma

What causes Mesothelioma?

Exposure to asbestos is responsible for the majority of cases. There are thought to be possibly other unknown causes. It has previously been a rare disease but is now occurring more frequently because of the heavy use of asbestos in the post-war years. For most people diagnosed with Mesothelioma the exposure happened 20-40 years previously. (It may in some instances be a longer or a shorter interval than this.) Sometimes the asbestos exposure may have been very brief and not always easy to identify. Mesothelioma is however more common in people who have had repeated exposure, usually in a work environment. There are several types of asbestos all of which have been known to cause Mesothelioma.

How is Mesothelioma diagnosed?

Early diagnosis is difficult and in most cases the first obvious sign is sudden breathlessness caused by an accumulation of fluid in the pleural space - a **pleural effusion**. It may be accompanied by other symptoms such as chest pain. Scans and X-rays can provide strong evidence to support the diagnosis especially coupled with a history of asbestos exposure. However, other diseases can produce these symptoms and to be certain of a correct diagnosis more investigations often need to be carried out.

Scans, Fluid taken for laboratory examination, possibly needle biopsy or keyhole surgery to take a biopsy (a small sample of tissue) are likely to be carried out to help with the confirmation of the diagnosis. These tests and results may take several weeks to complete.

Is there any treatment that may help?

Mesothelioma responds very little to the normal cancer treatments such as chemotherapy and radiotherapy. There are a number of trials being run in an attempt to improve treatment but nothing has been found to cure this disease. Any treatment offered depends on several factors. These should include patient choice, how well someone is, and how advanced the disease is.

The initial most helpful treatment is that which deals with symptoms. Removing fluid from around the lung can help to relieve breathlessness. Firstly the fluid may be drained either by drawing off fluid or inserting a small drainage tube. However the fluid often reaccumulates and the chest physician or surgeon may perform a procedure called a '**Pleurodesis**'.

Mesothelioma

This is an attempt to stick the lung surface to the chest wall by inserting sterile talc into the pleural space. This may be done by a surgeon using 'key hole surgery' otherwise called VATS - Video Assisted Thoracoscopic Surgery.

Surgery

There are minor forms of surgery which the surgeon may carry out during the VATS procedure which can involve removing some of the bulk of the tumour. Surgery may also improve some of the symptoms of the disease.

A very major operation which is called an **Extra-pleural Pneumonectomy (EPP)** is only suitable for a very select group of patients with early stage disease and who are physically and mentally able to tolerate such extensive surgery. The operation involves the removal of the whole affected lung along with its lining, the lining of the heart and part of the diaphragm. This operation is only carried out by a limited number of thoracic surgeons in the country.

Chemotherapy

This is drug treatment used to try to destroy or control cancer cells. Unlike some other cancers there is no evidence that chemotherapy ever cures Mesothelioma. Some trials and studies have however indicated that it may help to improve symptoms temporarily and may extend life expectancy slightly.

Not all patients with Mesothelioma will benefit from chemotherapy and there is no way of knowing which patients will benefit and which will not. It is important for you to discuss this with the doctors and nurses involved in providing it.

Radiotherapy

This is the use of high energy radiation to kill diseased cells in the body. In Mesothelioma it can be used in two ways:

- 1) A short course of treatment to the chest wall where a biopsy has been done. This is a preventative measure and is intended to stop Mesothelioma growing in the skin layer.
- 2) Some patients with pain may get some benefit from radiotherapy.

Mesothelioma

Will it spread to other parts of my body?

It is unusual for distant spread to be a problem. Mesothelioma spreads slowly outwards from its starting place, along the lining of the chest or abdominal wall, and problems experienced are usually confined to that locality and areas in close contact.

Will I have any pain? If so how can it be handled?

Because of the nature and position of the tumour near to the chest wall, some people with mesothelioma have aches and pains even before the diagnosis, whilst others have few problems with pain. It is important to realise that, if you are one of the unfortunate ones with early pain, this is not necessarily related to the extent of your disease - but more to do with where the mesothelioma is situated.

The pleural area is very well supplied with nerve endings which can easily be irritated or compressed by the tumour.

To maintain the quality of your life it is very important to be sure that you obtain adequate help with pain control if this is a problem for you. It is very rare for pain to be out of control and drugs are readily available which need to be given at the correct level and combination for the individual. You can ask for specialist help if you are having difficulties with pain. Hospice and Macmillan Nurses are available in most areas and your GP or hospital consultant can request help from them for you.

Mesothelioma

How can I help myself to stay as well as possible?

There is quite a lot you can do . . .

You can help yourself by maintaining your general health as much as possible i.e. a good balanced diet, preferably high calorie and rich in protein. If your appetite is not good, it may be beneficial to supplement your diet with specially balanced drinks which can be prescribed by your GP - or ask to see your hospital or community dietitian for advice.

Exercise is essential to maintain good muscle tone. If your energy level is low you can still do passive exercises of legs and ankles whilst sitting down.

If you are lacking in energy or get breathless on exertion, save your energy for the things you really want to do; make life as easy and convenient as you possibly can - and don't be too proud to accept help to achieve this (other people like to feel needed and useful).

Complementary therapies such as relaxation, massage and aromatherapy may be helpful in dealing with stress and anxiety.

What help is available if I need it?

Support is available from your GP and consultant. Many hospitals now have Lung Nurse Specialists or Macmillan Nurses who you may meet when the diagnosis is first made. Nursing help is available in the community and your local Community Nursing Sister should possibly be your first point of contact - preferably soon after the diagnosis. She can give ongoing support and can arrange practical help as needed.

Domestic help, adaptations to your house and loan equipment e.g. bathing aids can be provided via your local Social Services. They can also help with day-to-day living problems e.g. washing, dressing and cooking. These services are 'means tested' so it is important to claim benefits (see section 2) which will help cover any of these costs.

Mesothelioma

Who can I talk to?

Many people get emotional help from those friends and relatives closest to them. This, however, may not be enough and carers also, may feel the need for some support. Professional help and support is available in many areas and your GP or Community Nurse may be the best people to advise you about what is available locally - or you could phone one of the help lines given on pages 23 and 24 of this booklet. Perhaps you have contact with a minister who could help? Children and young people within your family need to know what is happening too. Don't feel they need to be protected and be as open and honest with them as their age allows. Their fear of what they imagine is often much worse than reality.

Please remember - 'Coping' does not mean the same as managing alone - and people often want to help, even if it's just by listening to your worries or doing errands for you. Haven't you ever felt good because you helped someone when they needed it? Allow those around you to feel good too.

Mesothelioma

Financial & Legal Aspects

It would be wise to seek assistance from your local Citizens Advice Bureau, a Local Benefits Adviser or Asbestos Diseases Support Group to help you through the tricky state benefits system!

Mesothelioma

2

Claiming Welfare Benefits

Department of Work & Pensions

The Department of Social Security (DSS) and the system of Benefit Agencies have been replaced by the Department of Work and Pensions (DWP) and an agency called Job Centre Plus.

To request benefit forms ring 0800 88 2200 (the DWP enquiry line). It is advisable to do this because if the benefit is awarded it will start at least from the date of that telephone call. They will also help with any queries you may have.

Always keep copies of any claim forms, letters or queries you may send or receive from the DWP. Record who you have spoken to, if you phone, and make a note of the date, time and reason for your call. Have your National Insurance Number available.

Always consider appealing against any decision disallowing your benefit (get help to do this).

Claim **ALL** benefits you even **THINK** you might be entitled to - many people miss out by failing to claim.

Pneumoconiosis Workers Compensation Scheme

If you are awarded Industrial Injury Disablement Benefit and seem unlikely to be able to claim Civil Compensation from a previous employer you can be entitled to an award under this scheme.

For application form and details ring 0800 279 2322
(if you get this award this may affect any means-tested benefits.)

Mesothelioma

Industrial Disablement Benefit or War / Military Pension

You can claim Industrial Disablement Benefit or War Pension but not both.

To be eligible to claim either of these benefits you must fit the following criteria.

- There must be a diagnosis of Mesothelioma
- You must be able to demonstrate that you came into contact with asbestos during the course of paid employment after July 1948, or during the course of Military Service.

Please note that this benefit, (although paid on top of many benefits) may reduce or lose you Income Support, Housing Benefit and Council Tax assistance.

To obtain claim forms -

For Industrial Disablement Benefit ring 0800 88 2200 ask for form B1 (100)
pn

For War Disablement Pension contact your local War Pensions Welfare Officer (under War Pensions Agency in the telephone directory)

or

enquire from the Veterans Help line 0800 169 2277

To speed up your claim for Industrial Benefits ask your Hospital Specialist Lung Nurse for form 100 BN/A. This is a confirmation of your diagnosis and you should enclose it with your Industrial Injury Disablement Benefit claim

The Disability Route (a very brief guide)

You can possibly claim at least one benefit from each box

1 Benefits to replace basic earnings because you cannot work (1a) or because you are caring for someone who cannot work (1b) or because you have recently been widowed (1c)

1a Statutory Sick Pay or Incapacity Benefit (National Insurance Contributions are needed).

1b Invalid Care Allowance.

1c Bereavement Payment plus Widowed Parents Allowance or Bereavement Allowance.

2 Benefits to compensate for the effects of Mesothelioma caused through your work or Military Service.

Industrial Disablement Benefit.
War Disablement Pension.

3 Benefits to assist with mobility/walking (under 65 years)

Disability Living Allowance (Mobility) Higher Rate, or Lower Rate.

4 Benefits to assist with personal care needs -

Disability Living Allowance (Care) under 65.

Attendance Allowance over 65.

Constant Attendance Allowance (no age limit).

Extra Severe Disablement Allowance (if you receive Constant, Att Allow. at one of the two upper rates).

Mesothelioma

5

Benefits to top up a low income.

Income Support
Working Family Tax Credit.

6

Benefits to assist with rent and council tax

Housing Benefit and Council Tax Benefit.

For example -

If your Mesothelioma has been caused through work and you have care and mobility needs, depending on your age and circumstances you could be claiming the following benefits.

Incapacity Benefit
Industrial Disablement Benefit
Constant Attendance Allowance
Extra Severe Disablement Allowance
Disability Living Allowance (mobility)

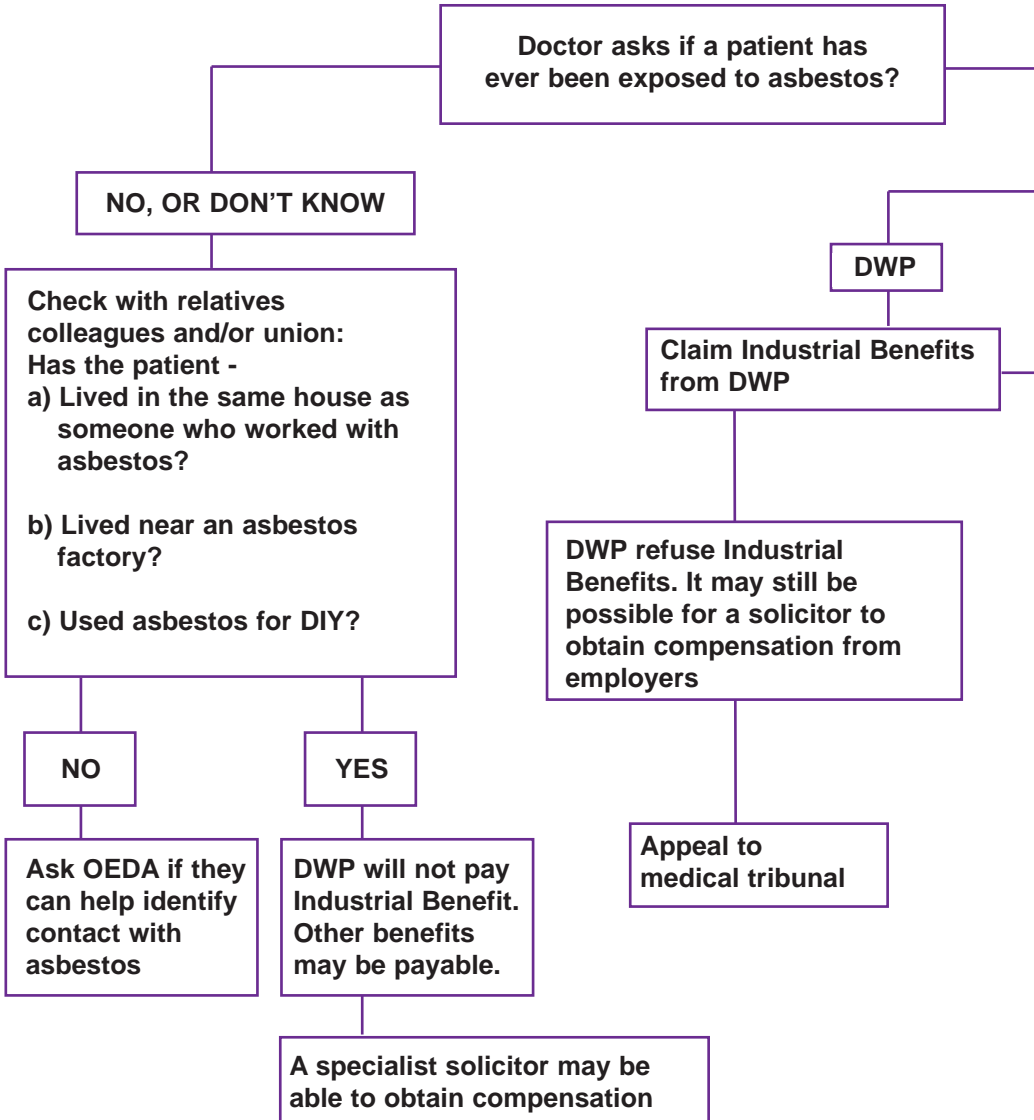
Plus possibly Income Support, Housing/Council Tax and Extra amounts for your carer/partner and/or children.

Do seek help with your benefit claims.

Mesothelioma

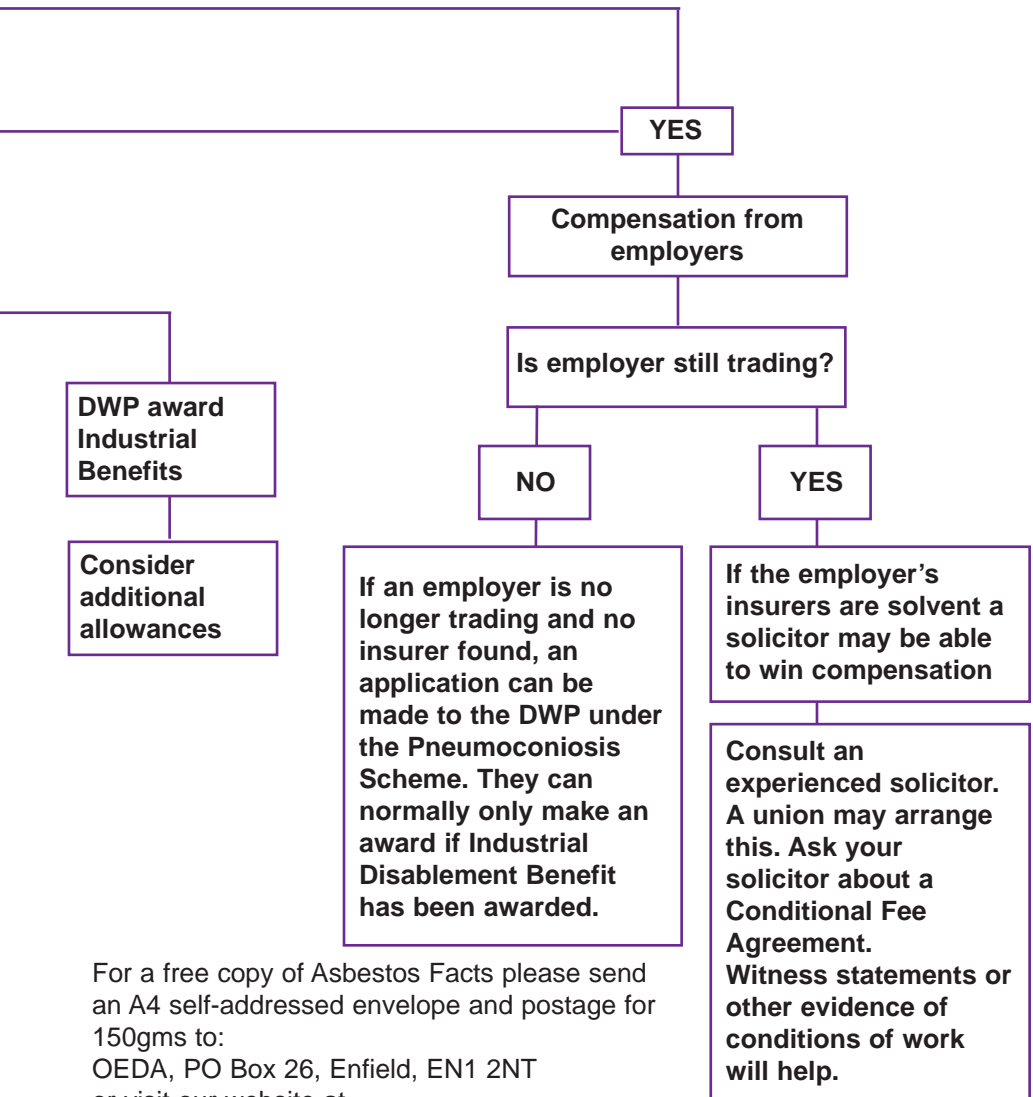
OEDA

Occupational & Environmental Diseases Association



Mesothelioma

Action Guide: Claims for DWP (Department of Work and Pensions - previously the DSS) benefits and compensation from employers, the asbestos industry or DWP Claim under Pneumoconiosis Scheme.



For a free copy of Asbestos Facts please send an A4 self-addressed envelope and postage for 150gms to:
OEDA, PO Box 26, Enfield, EN1 2NT
or visit our website at
<http://www.oeda.demon.co.uk>

Legal Questions & Answers

I have been diagnosed with mesothelioma. Should I see a solicitor?

Yes, if at all possible, as medical experts estimate that approximately 95% of all mesothelioma cases are caused by exposure to asbestos (usually in the workplace) and, more often than not, someone else (be it an employer, factory owner, or asbestos manufacturer) is to blame. Often people say “but, no one knew of the risks in those days; it was so long ago”, and put off the idea of taking legal advice, assuming nothing can be done. In actual fact, more often than not, there is a legal remedy, even if an employer has apparently ceased to exist. Therefore, it is unsafe to assume that no legal action can be taken.

Do I need to see a solicitor immediately?

Depending on the treatment you are receiving and how you are feeling, it is wise to take legal advice as soon as you possibly can as there are time limits for all personal injury claims. As a general rule a court action (“proceedings”) must be started within 3 years of the diagnosis (or from the time you first suspect that you are suffering from an asbestos related disease). Although the Court has a discretion to set aside the 3 year “limitation period” (as it is called), technically your claim would be time barred if you did not issue proceedings within the 3 years. In any event, given the poor prognosis, most people do not want to delay taking legal action. Since the civil justice system was reformed in 1999, claims do not tend to take as long as they did, but it is still possible to have a claim “expedited”, if the medical evidence suggests that someone’s life expectancy is very limited.

Can I go to any solicitor?

Most solicitors now tend to specialise; the days of the “general practitioner” are numbered. Even so, regrettably, some solicitors who are not experienced in this particular field do take on mesothelioma claims and that can have unfortunate consequences, especially as most employers’ liability insurance companies (on the other side) instruct specialist firms to defend such claims. In that situation, it would not be a level playing field. Therefore, it is always sensible to seek out a solicitor who specialises in asbestos related disease litigation. The Law Society (telephone number: 0870 606 2555), in London, has a list of specialist solicitors, as do various

Mesothelioma

victims of asbestos support groups (for example OEDA and Clydeside Action on Asbestos). Before instructing a solicitor, it is always worth asking about his/her qualifications and track record. For example, are they a member of the Law Society's Personal Injury Panel and/or the College of Personal Injury Law (CPIL). How many asbestos related disease cases have they successfully concluded within the last 3 years? Is the person you are dealing with a **qualified** solicitor?

Will it cost me a lot of money?

Although Legal Aid is now rarely available for personal injury claims, the 3 main funding options are:

- Conditional Fee ("no win: no fee") Agreement
- Trade Union funding
- Legal expenses insurance

As a consequence of changes introduced by the Access to Justice Act 2000, pursuing a personal injury compensation claim should not cost you a lot of money. Most (good) solicitors offer a free initial interview, even if a home visit is required (as is often the case). The solicitor should then discuss the various funding options at the outset, before any claim is intimated. If you are in a trade union/professional association, or have legal expenses insurance cover, then you may not have anything to pay, subject to the terms of the union agreement, or legal expenses insurance policy. If your solicitor is prepared to take the case on a "no win: no fee" basis, then you may have to pay a one off insurance premium (which is recoverable in the event of a successful claim). However, the insurance cover will protect you against the risk of having to pay the other side's costs in the event that the claim is lost or discontinued (provided court proceedings have been started). If you are successful, then the opposing party/insurance company will pay the claimant's basic legal costs and also a "success fee"* in addition. Following the introduction of the new rules, relating to costs, claimants are now in a much better position than they were and you may not have to pay anything at all if the solicitor operates a "no cost to you" policy. However, be aware that some firms/organisations offering "no cost" policies/deals may not necessarily have the relevant expertise, as they mainly deal with "fast track" (low value) personal injury claims. Industrial disease claims are complex and require skilful handling. [*This is the lawyers reward for taking the case on and facing the possibility that he/she will not be paid anything at all if the case is lost]

Mesothelioma

Will I have to appear in court?

Unlikely, as most personal injury claims are now settled, either before court proceedings are commenced, or before the final hearing (trial). A very small percentage of claims (about 1%) are assessed by a judge (at the trial stage). Therefore the chances of you appearing in court are slim, but not impossible. Your solicitor and legal team will explain the court process to you and, if there is a prospect of you having to give evidence in court, then you will be well prepared and well supported.

I am in a Trade Union/professional association - can they help me?

Very often, yes. It is a legal requirement that all the various funding options should be explained to you at the outset and, if there is a possibility that your membership organisation may fund your case, then that option should be explored. However, many trade unions, for example, are not prepared to provide legal aid/financial assistance if a person has ceased to be a member of that trade union, or if the relevant exposure (to asbestos) took place before they joined the union. Many former trade union members are therefore disenfranchised to that extent. However, with the advent of conditional fees, you should not be placed at any disadvantage, provided you can find a solicitor who is prepared to take on your case on a “no win: no fee” basis.

My relative died recently with mesothelioma - is it too late for me to take any legal action?

No, it is not too late as a claim can be brought by the executors/administrators of your partner's/relative's estate. Compensation can be claimed for your relative's pain and suffering and any financial losses which they suffered as a result of their illness, so it is still worth seeking legal advice. There may also be a claim by the surviving spouse/partner for bereavement damages and their reliance on the deceased person's income and contribution to household maintenance.

Mesothelioma

My partner has mesothelioma and is very ill and may not recover. Can we delay seeing a solicitor?

Although it is extremely important to obtain a detailed witness statement from the person who is suffering from mesothelioma, that is not always possible if the sufferer is extremely ill when the link with asbestos is first made. If that is the case, then the presence of a solicitor may be unwelcome. However, any handwritten notes or diary entries, which may be relevant, ought to be preserved, together with any work records (for example - deed of apprenticeship/indentures etc). The family can often give important evidence even though it is "indirect". However, there is no real substitute for the direct evidence given by the mesothelioma sufferer, him/herself. Their recollection of events is likely to be the most accurate. It is also worth making a note of the names and addresses of any former work colleagues who may be able to give evidence about the sufferer's exposure to asbestos.

I have been told that I probably have mesothelioma and I have been exposed to asbestos in the past. Should I see a solicitor even though the diagnosis is not 100% certain?

Mesothelioma is a notoriously difficult illness to diagnose accurately and even though there may be a clinical diagnosis, the doctors cannot always be 100% certain. Civil claims for damages (compensation) only have to be proved on the balance of probabilities (i.e. more likely than not) and therefore if the medical evidence states that it is likely that you are suffering from mesothelioma, then you should see a solicitor who may still be able to investigate a claim. Remember that the limitation period starts at the time when someone has a reasonable suspicion that they are suffering from an asbestos related illness, not from the time when a 100% diagnosis is made and so, from that point of view, it is wise to take legal advice promptly and the solicitor should then advise on the appropriate steps to be taken.

Special Note

Certain deaths have to be reported to the Coroner by the doctor who signs the death certificate - deaths from mesothelioma are in this category. When a death from mesothelioma is reported to the coroner, he then decides if a post-mortem examination is necessary and whether or not to hold an inquest. It is wise to request that samples be retained for detailed examination. You may wish to have legal representation at an inquest if there is a possibility of a civil claim.

In Scotland the law is slightly different as the Procurator Fiscal is notified.

Mesothelioma

Sources of Help and Information

Mesothelioma

3

Help & Information

Mesothelioma UK

0800 169 2409

DWP Benefit Enquiry Line

General advice on Benefits
Telephone help completing forms
Freephone for any enquiry

0800 88 2200

CancerBACUP

Information and support for people with
cancer, their families and friends
Helpline

0808 800 1234

Macmillan Cancer Relief

Information Line

0845 601 6161

Carers National Association Helpline

0808 808 7777

OEDA

PO Box 26, Enfield, Middlesex EN1 2NT
OEDA publishes material relating to asbestos
exposure. Scientific support for asbestos disease
claimants, information about specialist solicitors
and advice on claims. Telephone:

020 8360 8490

Scotland

CancerBACUP

0141 553 1553

Wales

Tenovus Cancer Information Centre
Helpline

0808 808 1010

Northern Ireland

The Ulster Cancer Foundation
Helpline

0289 066 3439

Mesothelioma

Mesothelioma, because of the association with previous employment and probable asbestos exposure, presents a complexity of problems relating to benefit claims and perhaps legal issues. It is advisable to talk to someone with specialist knowledge of these issues. There are several groups who can help you with this. Be very careful to use a recognised group and do not respond to adverts promising to get you compensation or benefits -

The following are asbestos victims support groups. They will provide free help and advice to anyone needing it.

Leeds **0113 231 1010**
(nurse available Tuesdays 10-4pm to answer any medical or nursing queries)

Sheffield **0114 282 3212**

Greater Manchester **0161 953 4037**

Bradford **01274 393949**

Derbyshire **01246 231 441**

North East **01642 240044**

Cheshire **01928 576641**

Liverpool **0151 236 1895**

Scotland

Clydeside Action on Asbestos **0141 552 8852**

Clydebank Asbestos Group **0141 951 1008**

Mesothelioma

Copies of this booklet can be obtained from the following:

The June Hancock Mesothelioma Research Fund
C/o Adrian Budgen,
St Peters House,
Sheffield S1 2EL
Tel 0114 274 4420

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

Mesothelioma UK
National Macmillan Mesothelioma Resource Centre
University Hospitals of Leicester NHS Trust
Glenfield Hospital
Hospital Management Offices
Grobby Road
Leicester LE3 9QP
Tel 0800 169 2409

If large numbers of booklets are required postage would be appreciated.

Mesothelioma

Useful web sites in the UK

www.leeds.ac.uk/meso

www.asbestos-action.org.uk

www.mesothelioma.uk.com

www.leedsthoracicsurgery.org.uk

Do you need someone to talk to?

If you would find it helpful to talk to someone who has had to cope with the problems of this disease as a carer, there are several volunteers prepared to try to help you in this way. Please ring Mavis Robinson on Tuesdays 10-4pm on 0113 231 10 10 and she will try to put you in contact. You may also look for help on the June Hancock website - www.leeds.ac.uk/meso or you could contact Meso UK 0800 169 2409.

Mesothelioma

Acknowledgements

My thanks to the following for their invaluable help in the compilation of this booklet.

And also for contributions to the content of the booklet.

Carolynne Radcliffe *Welfare Law Training Consultant*

Adrian Budgen *Solicitor*

Nancy Tait MBE *Occupational and Environmental Diseases Association*

Dr MF Muers *Respiratory Physician*

Mr JG Edwards *Clinical Research Fellow*

Jo Vernon *Coroners Officer*

Liz Darlison *Nurse Consultant*

Mavis Robinson MBE

This booklet has been financially supported by
The June Hancock Mesothelioma Research Fund

c/o Adrian Budgen

St Peters House, Hartshead,
Sheffield S1 2EL.

Tel: 0114 274 4420

in association with the British Lung Foundation.

Donations to improve knowledge and promote research about Mesothelioma are always welcome.