Gateway Ref: 7907

Mesothelioma Framework

Advice for the NHS on how to organise services for
Malignant Pleural Mesothelioma (MPM) patients
to improve quality of care across the country

27 February 2007

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Foreword by the National Cancer Director

Approximately 1800 new cases of mesothelioma are diagnosed each year in England. The large majority of patients will die within a year of diagnosis and only a very small minority will survive 5 years.

It is imperative that mesothelioma patients should be diagnosed as early as possible, offered radical treatment where this is appropriate, have access to optimal palliative interventions and care and be offered appropriate information and advice including on financial benefits and possible compensation.

This Framework has been developed by the Department of Health on advice from members of its Lung Cancer and Mesothelioma Advisory Group and from the British Thoracic Society. It includes comments received during consultation with cancer networks, professional groups and patients groups. I would like to thank all those who have contributed.

I have no doubt that implementation of the recommendations in this Framework will improve quality for care for patients with mesothelioma.

Professor Mike Richards
National Cancer Director

Introduction

Who is the framework for?

1. This framework aims to provide Strategic Health Authorities (SHAs), cancer networks, Primary Care Trusts (PCTs) and NHS Trusts in England with advice on how to organise services for mesothelioma patients in order to improve quality of care to a uniformly high level across the country. It includes advice on:

    a. Configuration of services;
    b. Raising Awareness;
    c. Clinical management;
    d. Underpinning programmes such as information, research and audit.

2. The framework is intended as service guidance rather than a detailed clinical guideline i.e. it offers recommendations on the organisation of services to ensure improved care and outcomes for mesothelioma patients. It assumes that good practice has been followed in terms of delivering a patient centred service as set out in the guidance issued by the National Institute for Health & Clinical Excellence (NICE) on "*Improving Supportive & Palliative Care for Adults with Cancer*" issued in March 2004 and that measures on lung cancer multidisciplinary (MDT) membership and meetings, as set out in the 2004 Manual for Cancer Services, have been met.

3. The uptake of this framework is not mandatory. However, the developers of the framework believe that adoption of the recommendations would make a substantial difference to mesothelioma patients and their families and that it can be implemented relatively simply and is largely cost neutral as it builds on service structures already in place for lung cancer.

4. This framework should be read in conjunction with the 2001 British Thoracic Society Statement on Malignant Mesothelioma in the United Kingdom (which is currently being revised). The British Thoracic Society has collaborated closely with formulating the final version of this framework to ensure that it will be complementary and mutually supportive of their revised statement due to be published later this year.

5. This framework is not intended to be a patient information leaflet. However, the British Lung Foundation will produce a guide for patients setting out what they can expect from the NHS if this framework has been implemented locally.

Reason for Framework

6. There are around 1800 new cases of mesothelioma a year in the UK and the disease is almost always fatal. More people die of mesothelioma than of cervical cancer, malignant melanoma or endometrial carcinoma. Mesothelioma incidence is still rising and is expected to peak between 2010 and 2015. Between 2006 and 2020 up to 30,000 people will die of the disease in the UK.

7. A proposal for a NICE mesothelioma clinical guideline was considered by the Department of Health in September 2002 but it was decided that there was insufficient evidence at the time for NICE to be asked to produce evidence-based guidance. This position remains unchanged. There are also no plans to produce Improving Outcomes Guidance (IOG) on this disease.

8. The Department of Health's Lung Cancer and Mesothelioma Advisory Group (LCAMAG), chaired by the National Cancer Director, and its associated Mesothelioma Working Group (MWG) therefore advised that, in the absence of a clinical guideline or an IOG, the Department should agree to the production of a framework offering advice to the NHS on how to improve services for mesothelioma patients. The department agreed to this given the issues set out below which, when taken together, show that mesothelioma is a particularly challenging condition to manage:

    a. in parts of the country, mesothelioma is a relatively rare condition and there are few, if any, dedicated multi-disciplinary teams (MDTs) for mesothelioma;
    b. mesothelioma can be difficult to diagnose;
    c. patients often have a short life expectancy and experience complex, debilitating symptoms. Earlier detection could mean increased potential for radical therapy in a small minority of patients which could increase their length of survival;
    d. for those patients with more advanced disease, there may be major quality of life issues which could benefit from a range of specialist advice, for example, on symptom control;
    e. in most cases, mesothelioma is an industrial disease which leads to complicated legal and financial information needs plus a coroner's inquest once a patient has died;
    f. psychosocial issues often need to be addressed as patients and their families come to terms with the diagnosis of an incurable disease which is often industrially related;
    g. more research is necessary if outcomes are to be improved;
    h. a peak in mortality is less than 10 years away so there is a real opportunity to ensure that the NHS has done all it can to provide a high quality service for the increasing number of patients that will be diagnosed with mesothelioma over the next few years.

9. This document is the resulting framework. It is not a formal evidence-based clinical paper, but service guidance based on professional consensus about what is deemed good practice in organising mesothelioma services and caring for mesothelioma patients and their families. It takes into account the key messages from the Mesothelioma Patients' Charter developed by the British Lung Foundation in collaboration with patients and their families along with comments received during a 7 week consultation and relevant evidence where available.

10. The framework is supported by the Department of Health's Lung Cancer & Mesothelioma Advisory Group (LCAMAG), the National Lung Cancer Forum for Nurses, the British Lung Foundation and Cancer Research UK. It has also been produced in close collaboration with the British Thoracic Society.

11. LCAMAG advise that care for patients with mesothelioma in this country could be improved substantially by implementation of this framework.

Key recommendations

12. It is recommended that:

a. all patients with diagnosed mesothelioma (and undiagnosed unilateral pleural effusion where mesothelioma is a possible diagnosis) should have their case discussed by a lung cancer MDT and a number of these MDTs should be designated as specialist MDTs to advise on the diagnosis of more difficult mesothelioma cases and, in some cases, the management of patients. It will be important that:

   i. all MDTs that manage mesothelioma patients participate in the National Lung Cancer Audit Programme (LUCADA);
   ii. the lung MDTs, in association with their specialist MDT where appropriate, consider treatment and care options, including psychosocial needs, for all mesothelioma patients before a treatment/care plan is discussed and agreed with the patient;
   iii. palliative care and symptom control is central to any management plan for mesothelioma patients;
   iv. all appropriate mesothelioma patients are offered the option of entering a clinical trial, where one relevant to their clinical condition is open for recruitment.

b. Each cancer network should have a lead clinician and lead nurse for mesothelioma with an agreed list of responsibilities and time set out in their job description (for the clinician, expressed in whatever units are used in their contract) to carry out those responsibilities.

c. PCTs in areas associated with asbestos-related industries/high mesothelioma incidence consider targeted local initiatives in primary care (and perhaps local hospitals) to:

   i. maintain among local clinicians a higher level of suspicion of the disease in appropriate patients than may be necessary in other parts of the country;
   ii. ensure all local clinicians know what to do if they have a suspicion of mesothelioma ie. when and where to refer patients for specialist advice.

d. All mesothelioma patients have a key worker (this is likely to be the lung Clinical Nurse Specialist initially) who should be able to facilitate referrals/contact with members of the extended MDT as required until such time as it is agreed that a member of the palliative care team should take over this role. Clinical Nurse Specialists should also be responsible for:

   i. the provision of information to patients and their families in a timely manner and within a supportive environment;
   ii. ensuring that a patient’s level of understanding is assessed, documented and communicated throughout the care pathway;
   iii. ensuring patients are signposted to information on benefits and legal advice on possible compensation.

Background

What is mesothelioma?

13. Mesothelioma is a cancer which principally affects the lining of the lungs (pleura). However it can also affect the peritoneum (a thin lining in the abdomen), and occasionally, arises in the membranes covering either the testes (tunica vaginalis) or the heart (pericardium). Over 90% of mesothelioma with a known first site occurs as pleural mesothelioma. This is the subject of this framework.

What causes mesothelioma?

14. Mesothelioma has a very strong association with exposure to asbestos and is exceedingly rare in its absence. When asbestos fibres are inhaled, malignant change occurs in a proportion of individuals and cancer of the pleura can follow. It is believed that nearly all deaths caused by mesothelioma are linked to asbestos exposure.

15. There is a long ‘lag time’ between exposure to asbestos and the development of mesothelioma; this varies from a minimum of about 10 years upwards, the average interval being in the order of 30-40 years.

16. Cases of mesothelioma in the UK used to occur mainly in people who had worked in ship building and heavy engineering (which used significant amounts of asbestos) and asbestos product manufacturing industries. For this reason, mesothelioma was more common in areas such as Scotland, the North East and Southern England where many of these industries were based.

17. An increasing proportion of cases are now being diagnosed in individuals who may have had less intense exposure such as the building industry (carpenters, electricians, demolition workers etc.) and people who have worked in buildings where asbestos construction materials have been used and become disturbed in some way. It is estimated that these now represent the majority of new cases and therefore there is a large number of people who are at risk of the disease who may be unaware of their exposure to asbestos.

18. Men are far more likely to develop mesothelioma than women, mainly because they were more likely to have been exposed to asbestos in the course of their work than women were. However, family members of people exposed to asbestos also have a higher risk of developing mesothelioma because of fibres brought into the home on work clothes. A third group of cases probably arise because of ‘environmental’ exposure, for example in individuals who have lived in close proximity to asbestos factories or dumping sites. There is also a small number of deaths each year in people with no history of asbestos exposure – evidence suggests that there are likely to be at least 50 of

these so-called “spontaneous” mesothelioma cases each year in Great Britain.

19. The use, supply and importation of asbestos and asbestos products is now banned for all but a few exceptions by the Asbestos (prohibition) Regulations. Work with asbestos generally requires a licence and the use of strict control measures, including personal protective equipment such as respirators. The latest revision of the Control of Asbestos at Work Regulations introduced, from May 2004, a duty on those responsible for commercial premises to manage the asbestos contained in them (source: www.HSE.gov.uk).

Epidemiology

Incidence

20. There were 1,834 newly diagnosed cases of mesothelioma registered in England in 2004 of which 1,534 (84%) cases were in males and 300 (16%) in females. In a study in the Yorkshire region between 2002 and 2005, the median age at diagnosis was 74.6 (range 36 – 93)[1]. The median age is slowly increasing because of the exposure of a cohort of individuals to asbestos in the 1960s and 1970s. Mesothelioma is predicted to become more common over the next 5-10 years as the effects of this exposure become apparent and it is estimated that around 1% of all males born between 1940 and 1950 will die of the disease[2].

21. There is variation in the incidence of mesothelioma around the country as shown in the following table:

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[1] Chapman A, Mulrennan S, Ladd B, Muers M, Population based epidemiology and prognosis of mesothelioma in Leeds UK. Thorax 2005 60 SII 73

[2] Peto, J., Hodgson, J.T., Matthews, F.E., Jones, J.R. Continuing increase in mesothelioma mortality in Britain. *Lancet* 1995; **345** (i): 535-539

Incidence of mesothelioma (ICD10 C45), persons by SHA, 2004

		Numbers	Population	Crude rate[1]	Age-standardised rate[1,2]	Lower Confidence Intervals	Upper Confidence Intervals
Q01	NORFOLK, SUFFOLK AND CAMBRIDGESHIRE	84	2238151	38	24.9	19.4	30.5
Q02	BEDFORDSHIRE AND HERTFORDSHIRE	42	1617537	26	21.1	14.5	27.7
Q03	ESSEX	60	1635605	37	27.1	20.1	34.2
Q04	NORTH WEST LONDON	42	1834066	23	23.1	15.9	30.3
Q05	NORTH CENTRAL LONDON	26	1227957	21	20.6	12.4	28.8
Q06	NORTH EAST LONDON	57	1531427	37	41.2	30.2	52.2
Q07	SOUTH EAST LONDON	60	1514122	40	37.7	27.7	47.7
Q08	SOUTH WEST LONDON	26	1321018	20	20.9	12.7	29.0
Q09	NORTHUMBERLAND, TYNE & WEAR	97	1396374	69	47.5	37.6	57.3
Q10	COUNTY DURHAM AND TEES VALLEY	54	1148699	47	35.4	25.7	45.1
Q11	NORTH AND EAST YORKSHIRE AND NORTHERN LINCOLNSHIRE	52	1652387	31	21.7	15.5	27.8
Q12	WEST YORKSHIRE	81	2108028	38	30.7	23.7	37.7
Q13	CUMBRIA AND LANCASHIRE	80	1929653	41	29.3	22.6	35.9
Q14	GREATER MANCHESTER	82	2539043	32	28.2	22.0	34.4
Q15	CHESHIRE & MERSEYSIDE	110	2358474	47	32.2	26.0	38.4
Q16	THAMES VALLEY	72	2120859	34	28.5	21.7	35.3
Q17	HAMPSHIRE AND ISLE OF WIGHT	96	1801442	53	37.5	29.6	45.3
Q18	KENT AND MEDWAY	74	1610310	46	33.6	25.7	41.5
Q19	SURREY AND SUSSEX	114	2577631	44	29.5	23.7	35.3
Q20	AVON, GLOUCESTERSHIRE AND WILTSHIRE	97	2206246	44	32.8	26.0	39.6
Q21	SOUTH WEST PENINSULA	84	1619062	52	32.7	25.4	40.1
Q22	SOMERSET AND DORSET	45	1212892	37	23.3	16.1	30.5
Q23	SOUTH YORKSHIRE	37	1278434	29	22.9	15.3	30.5
Q24	TRENT	70	2687496	26	17.9	13.6	22.2
Q25	LEICESTERSHIRE, NORTHAMPTONSHIRE AND RUTLAND	47	1592211	30	21.4	15.1	27.8
Q26	SHROPSHIRE AND STAFFORDSHIRE	43	1499568	29	21.2	14.7	27.8
Q27	BIRMINGHAM AND THE BLACK COUNTRY	53	2274964	23	17.9	12.9	22.9
Q28	WEST MIDLANDS SOUTH (PREVIOUSLY COVENTRY, WARWICKSHIRE, HEREFORDSHIRE AND WORCESTERSHIRE)	49	1559474	31	22.6	16.1	29.1

Source: Office for National Statistics

1 rate per million population
2 Age-standardised to the European standard population

22. This shows that, of the then 28 SHAs:

    a. 9 had between 25-49 cases a year;
    b. 9 had between 50-74 cases a year;
    c. 8 had between 75-99 cases a year;
    d. 2 had over 100 cases a year.

    In relation to cases per million, there was at least a threefold variation between SHAs (range 20 - 69).

23. Thus in some areas, mesothelioma can be considered a rare disease. This is even more noticeable if data is considered at Primary Care Trust (PCT) level. In 2004 according to ONS figures, based on the current PCT (152) boundaries:

    a. 14% of PCTs had less than 5 cases of mesothelioma a year;
    b. 33% of PCTs had between 5-9 cases of mesothelioma a year;
    c. 23% of PCTs had between 10-14 cases of mesothelioma a year;
    d. 14% of PCTs had between 15-19 cases of mesothelioma a year;
    e. 16% of PCTs had more than 20 cases of mesothelioma a year.

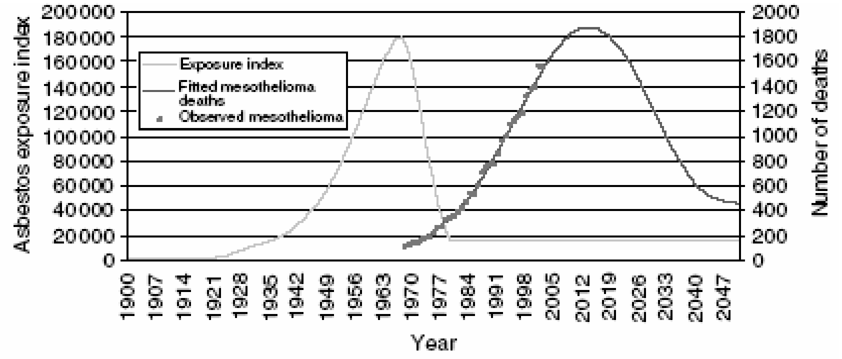
24. The Health & Safety Executive (HSE) has found that the geographical variation in incidence is associated with the geographical locations of asbestos related industries. High risk areas tend to be those containing, or near to, industrial sites where asbestos was used extensively in the past – shipyards, asbestos manufacturing factories and railway engineering works for example (source: www.hse.gov.uk).

Mortality

25. Information from the Health & Safety Executive (HSE) also shows that the annual number of mesothelioma deaths is increasing from 153 in 1968 to 1633 in 2000 to 1969 in 2004. The annual total number of mesothelioma deaths in Great Britain is predicted to peak during the period 2011 to 2015 at a level up to 2450 deaths per annum.

26. The following graph shows the number of deaths from mesothelioma since the mid 1960s and those that are predicted to take place over the next 40 years or so. It also shows how this trend correlates to asbestos exposure from the 1900s to the 1980s. It can be seen that there is a lag of around 45 years from the peak of exposure to the peak in deaths[3].

Observed and fitted mesothelioma deaths by year of deaths, with derived exposure index



27. At Local Authority level there is huge variation in the Standardised Mortality Ratio (SMR) for mesothelioma around the country. In men, over the period 1981-2000 the SMR varied from 593 in Barrow-in-Furness to 16 in Worcester. Again, this is likely to be related to the geographical location of asbestos-related industries. The following table shows the Local Authorities (LAs) in England with the highest and lowest SMRs for men and women between 1981-2000:

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[3] J Peto et al, British Journal of Cancer (2005) 92, 587 – 593)

LAs in England with the highest SMRs for Mesothelioma 1981-2000

Males			Females		
Area	**SMR**	**No.***	**Area**	**SMR**	**No.***
Barrow-in-Furness	593	7	Barking & Dagenham	649	2.6
Plymouth	396	15.9	Sunderland	575	4
Portsmouth	388	11.1	Blackburn	484	1.5
South Tyneside	357	9.3	Newham	348	1.4
North Tyneside	340	11	Leeds	328	5.7
Southampton	325	10.3	S Ribble	367	0.8
Eastleigh	303	4.7	Swale	297	0.8
Medway	298	9.4	Kirklees	226	2
Barking & Dagenham	294	7.3	Chorley	279	0.6
Newham	250	6.8	Southampton	221	1.1

LAs in England with lowest SMRs for Mesothelioma 1981-2000

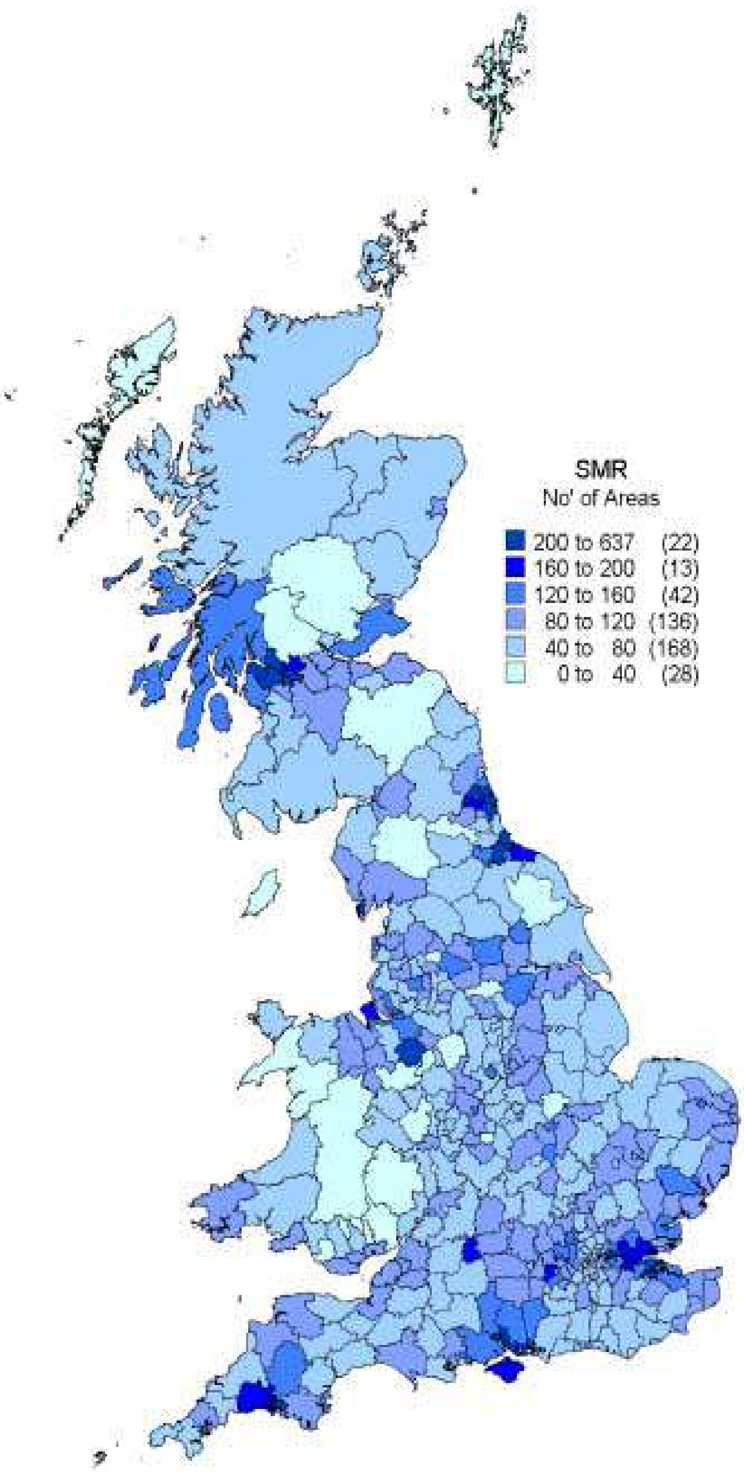
Males			Females		
Area	**SMR**	**No.***	**Area**	**SMR**	**No.***
Kensington & Chelsea	39	0.75	Canterbury	26	0.1
Herefordshire	34	1	Rotherham	26	0.15
Newcastle-u-Lyme	30	0.6	Doncaster	22	0.15
Cheltenham	29	0.5	Warwick	17	0.05
Ryedale	27	0.25	Eastbourne	15	0.05
Staffordshire	25	0.4	Brighton & Hove	14	0.1
Barnsley	22	0.8	Wealden	12	0.1
Worcester	16	0.2	Hinckley & Bosworth	0	0

*Denotes the average number of new cases per annum over the 1981-2000 time period.

Source: Health & Safety Executive

Please note that this data is from 1981 to 2000 and has been included for comparative purposes between regions only. It does not reflect the current incidence rates although wide geographical variation is still expected to exist.

28. The following map of Great Britain shows male SMR for mesothelioma by local and unitary authorities – the areas with the highest SMRs are clear to see:



Survival

29. Mesothelioma is almost always fatal. Median survival from diagnosis varies from study to study mostly within the range of 8 to 9 months although some studies show a range up to 14 months. The one-year survival rate for adults diagnosed with cancer of the pleura (almost all mesotheliomas) during 1991-2001 was under 30% and five-year survival was 3-4%.

30. The survival rate for mesothelioma is poor compared with other cancers. This is thought to be due to the advanced nature of mesothelioma at the time of diagnosis and the lack of effective treatments. However, with earlier detection and improved services it could be possible to extend and improve the quality of life of mesothelioma patients and there is the potential for radical therapy in a small minority of patients which could significantly increase their length of survival. At the very least, such early stage patients should have the opportunity to be entered into high quality trials of new therapeutic approaches.

Activity/Current Services

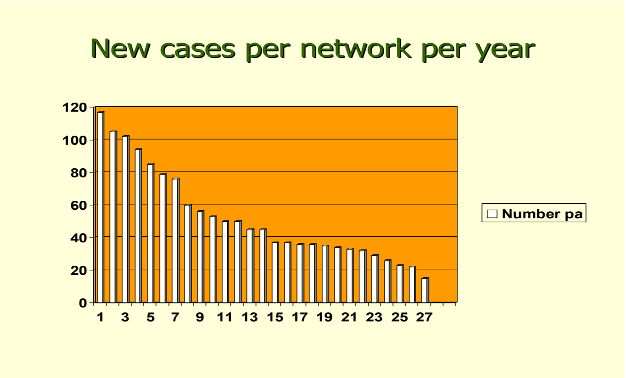
31. A questionnaire was sent to all the clinical and nursing mesothelioma leads in England in 2005 to find out more about local mesothelioma services and referral issues. 27 of the then 34 Networks responded (79%). Of the approximately 155 lung cancer multidisciplinary teams (MDTs) in England, 124 (80%) were referred to in these responses although it is likely that all lung MDTs, on occasion, deal with patients with mesothelioma as well as lung cancer.

32. The following table shows the reported numbers of mesothelioma cases per annum from the 27 networks that responded to the questionnaire along with the number of MDTs that were reporting on mesothelioma patients in that period within each network:

Network	**Reported numbers pa**	**No. of MDTs reporting on mesothelioma patients pa**
3 Counties	23	4
Arden	34	3
Avon Somerset & Wilts	60	7
Black Country	15	2
Cancer Care Alliance	53	4
Central South Coast	105	4
Derby Burton	22	2
Dorset & Somerset	29	3
Greater Manchester	117	10
Kent & Medway	76	4
Lancashire & South Cumbria	50	6
Leicestershire Northampton & Rutland	37	3
Merseyside & Cheshire	85	12
Mid Anglia	26	3
Norfolk & Waveney	32	4
North London	35	6
North Trent	56	6
North West Midlands	31	4
Pan Birmingham	102	6
Peninsula	79	5
SE London	50	6
South Essex	36	2
SW London	45	1
Surrey West Sussex & Hampshire	37	4
Sussex	36	4
Thames Valley	45	2
Yorkshire	94	8
Total (27 networks)	**1410**	**125**
Average number pa	**52**	**11.3**

33. This shows that:

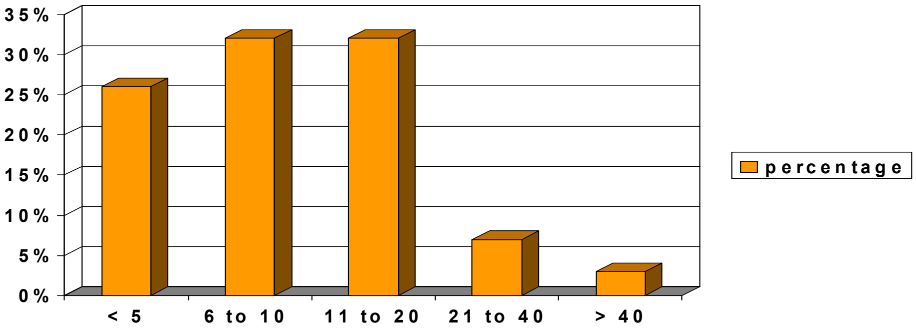
a. the mean number of cases being seen annually by networks was 52, ranging from 15 – 117.



b. the mean number of cases being seen by each MDT per year was 11.3 with a range of 1 – 54 and more than half of the MDTs see 10 cases or less a year:

i. 26% of MDTs see 5 cases or less a year;
ii. 32% of MDTs see between 6-10 cases per annum;
iii. 32% of MDTs see between 11-20 cases per annum;
iv. 7% of MDTs see between 21-40 cases per annum;
v. 3% of MDTs see more than 40 cases of mesothelioma a year.

Number of new cases per MDT per year



34. In addition, responses from the survey showed that:

a. 96.5% of MDTs estimated that they discuss most or all reported mesothelioma cases with 3.5% estimating that they only discuss difficult or unusual cases;
b. some MDTs may go up to 6 months without seeing a single mesothelioma case;
c. 99% of MDTs had a clinical nurse specialist, 89% had an oncologist and 78% had a thoracic surgeon in regular (>50%) attendance.

Improving services for mesothelioma patients

35. The following section addresses:

a. Configuration of services:

   i. Cancer Networks
   ii. MDTs

b. Raising Awareness

c. Clinical management:

   i. Diagnosis
   ii. Treatment
   iii. Supportive & Palliative Care
   iv. Clinical Nurse Specialists

d. Underpinning programmes

   i. Communication, information and support
   ii. Research/clinical trials
   iii. Audit and patient surveys

Configuration of Services

Cancer Networks

36. Cancer networks play a key role in ensuring integrated care, improved clinical outcomes, cost effective services, improved patient experience and equity of service provision. In areas such as mesothelioma where incidence is low compared to other cancers and there is no prospect of NICE or Improving Outcomes guidance, it is easy for the disease to be overlooked. To help avoid this, in 2005, each Cancer Network was asked to nominate a clinical and a nursing lead for mesothelioma. ***It is <u>not</u> intended that these leads are responsible for the clinical management of all mesothelioma patients in the network***, rather they should help ensure that the network has appropriate individuals, processes and protocols in place to identify and manage these patients in accordance with this framework.

37. As at December 2005 all but one of the then 34 cancer networks already had a lead nurse and lead clinician in place for mesothelioma. Of the 33 lead clinicians 17 were respiratory physicians, 10 were oncologists, 3 were thoracic surgeons, 1 was a radiologist and for 2 their background was unknown.

Recommendations

38. It is recommended that:

    a. Each cancer network should have a lead clinician and lead nurse for mesothelioma.

    b. Each lead clinician/nurse should have an agreed list of responsibilities (in line with the role set out at para 38c). They should also have time set out in their job description (for the clinician, expressed in whatever units are used in their contract) to carry out those responsibilities. The time needed may differ between networks and administrative support may be needed.

    c. The role of the network mesothelioma clinical and nursing leads should be:

        i. to benchmark clinical activity for the past year, for example bringing together data on the incidence of mesothelioma in their network and the numbers of patients being discussed at each of their MDTs, in order to establish the baseline position locally and to monitor trends and changes in practice;
        ii. to carry out a mesothelioma needs assessment for their local population, if one has not been done in the last 12 months, to identify the nature of any problems and how they might be resolved (this would include the availability of the relevant clinical expertise within their network);

iii. to assist/support the implementation of this framework, for example by:

  - ensuring specialist MDTs are in place in line with paras 44 c-j;
  - ensuring, in consultation with the lung cancer network site specific group, that referral pathways are clear & relevant protocols developed that can take into account the circumstances and preferences of individual patients;
  - supporting cross network co-ordination/ communication including ensuring that efficient arrangements are in place for the timely transfer of notes, images and pathological specimens between MDTs;
  - ensuring that details of relevant clinical trials are available to their MDTs;
  - ensuring that lung MDTs submit data on all mesothelioma cases to the National Lung Cancer Audit Programme (LUCADA) - see para 80;
  - ensuring (even once the framework is implemented), that local population needs are regularly reviewed and that there is on-going audit and feedback to the network about the quality of services provided;
  - acting as a mesothelioma ‘resource’ for the local area including a role in encouraging colleagues in MDTs to undertake appropriate education and training.

iv. to contribute to the recently established network of mesothelioma leads which seeks to share experiences and good practice with the aim of improving services for this group of patients nationally.

Multi-disciplinary Teams

39. A consistent theme in the "Improving Outcomes" series of cancer guidance is that cancer services are best provided by teams of clinicians who work together effectively. The NHS Cancer Plan, 2000 stated that "*the care of all patients with cancer should be formally reviewed by a specialist team*".

40. It is important that mesothelioma patients have their cases discussed by a multi-disciplinary team (MDT) to ensure optimal management. Patients managed by MDTs are more likely to:

    a. be offered a range of effective interventions rather than investigations and treatments determined by an individual doctor's specialisation;

    b. receive better coordination and continuity of care through all stages of their disease;

    c. be treated in accordance with locally-agreed protocols and clinical guidelines;

    d. be offered appropriate and consistent information;

    e. have psycho-social as well as clinical issues considered thus improving the overall experience of care.

41. In addition:

    a. staff working in multidisciplinary teams are likely to develop higher levels of knowledge, skills, expertise and experience thus ensuring higher quality diagnosis, treatment and care for mesothelioma patients;

    b. establishment of multidisciplinary teams tends to reduce the variation in management and outcomes around the country and in particular avoid individual 'outliers' who may provide sub optimal care.

42. The extent to which mesothelioma patients are currently discussed in MDTs is variable. Anecdotal evidence suggests that there are few (if any) dedicated mesothelioma MDTs around the country. It is estimated that around 90% of mesothelioma patients have their case discussed as part of a lung cancer MDT but some of these MDTs only focus on the difficult or unusual cases leaving some mesothelioma cases not discussed by an MDT at all. This runs counter to the statement in the NHS cancer plan (see para 39).

43. The general consensus is that dedicated mesothelioma MDTs are not necessary and the existing lung MDTs provide the appropriate infrastructure to discuss and manage mesothelioma patients unless the caseload becomes very heavy. However, there is a recognition that diagnosis staging and management of some mesothelioma cases is more difficult than others and may require a higher level of expertise than could be reasonably expected from all lung MDTs.

Recommendations

44. It is recommended that:

    a. all patients with diagnosed mesothelioma or an undiagnosed unilateral pleural effusion, where mesothelioma is a possible diagnosis, should have their case discussed by a lung cancer MDT.

    b. lung MDTs should confirm the diagnosis of mesothelioma where possible, based on radiological images and pathology reports available at the meeting, and manage patients with advanced mesothelioma who are unfit for radical treatment/ trials or who have palliative and supportive care needs only.

    c. a number of existing lung MDTs should be designated as specialist MDTs to advise on the diagnosis of more difficult mesothelioma cases and, in some cases, the management of patients.

    d. specialist MDTs should provide advice for the following groups of patients:

        i. patients in whom there are local difficulties with diagnosis or staging (estimated at around 20% of mesothelioma patients);

        ii. patients with a performance status (PS) of 0-2 (estimated at around 43% of mesothelioma patients) where chemotherapy, radical treatment including surgery or multimodality therapy, or trial entry may be an option;

        It is estimated that this would mean that advice would be needed from a specialist MDT for around 60% of all new/suspected mesothelioma cases - nationally this would be around 1080 cases a year which, if evenly distributed across the country, would amount to approximately 34 patients per network (ie. less than one case per week in most networks). Video-conferencing should be considered where appropriate.

    In addition, the specialist MDT should:

        iii. inform the referring clinician when the patient is being discussed at the Specialist MDT and invite them to attend the meeting if they so wish;

    iv. review the pathological and radiological basis for the diagnosis, particularly in all patients where radical treatment is being considered;

    v. manage patients who are fit for radical surgical or multi-modality treatment (patients considered possible candidates for extrapleural pneumonectomy or radical debulking surgery may need to be referred onwards to one of the other specialist MDTs if they don't have the appropriate surgical expertise);

    vi. make recommendations with regard to the appropriateness of chemotherapy although the location of chemotherapy administration should be agreed locally within the network;

    vii. actively encourage the recruitment of appropriate patients to relevant national clinical trials.

e. designation of certain lung MDTs as specialist MDTs should be for local determination following a review of the mesothelioma caseload and discussion with stakeholders including the cancer network and local specialist commissioning group. These MDTs need not necessarily be based at university or teaching hospitals. A district general hospital could equally well host a specialist MDT if that is where the necessary expertise is located. It is however expected that most specialist MDTs will be based around centres with thoracic surgical services or where there are visiting surgeons with expertise in this area.

f. a specialist MDT would need a reasonable throughput of cases in order to develop and maintain expertise - a minimum of 25 mesothelioma cases a year is suggested. The survey results (see para 32), indicate that an annual caseload of 25 is likely to enable the designation of one specialist MDT in most networks.

g. where the caseload is not sufficient to support a specialist MDT within the boundaries of a network a protocol to support referrals to another network's specialist MDT should be put in place.

h. the membership of the designated specialist MDT would be the same as that for the lung MDT. However, the respiratory physician, thoracic surgeon, oncologist, clinical nurse specialist, imaging specialist, pathologist and member of the palliative care team would need to have, or develop, a specialist interest in mesothelioma.

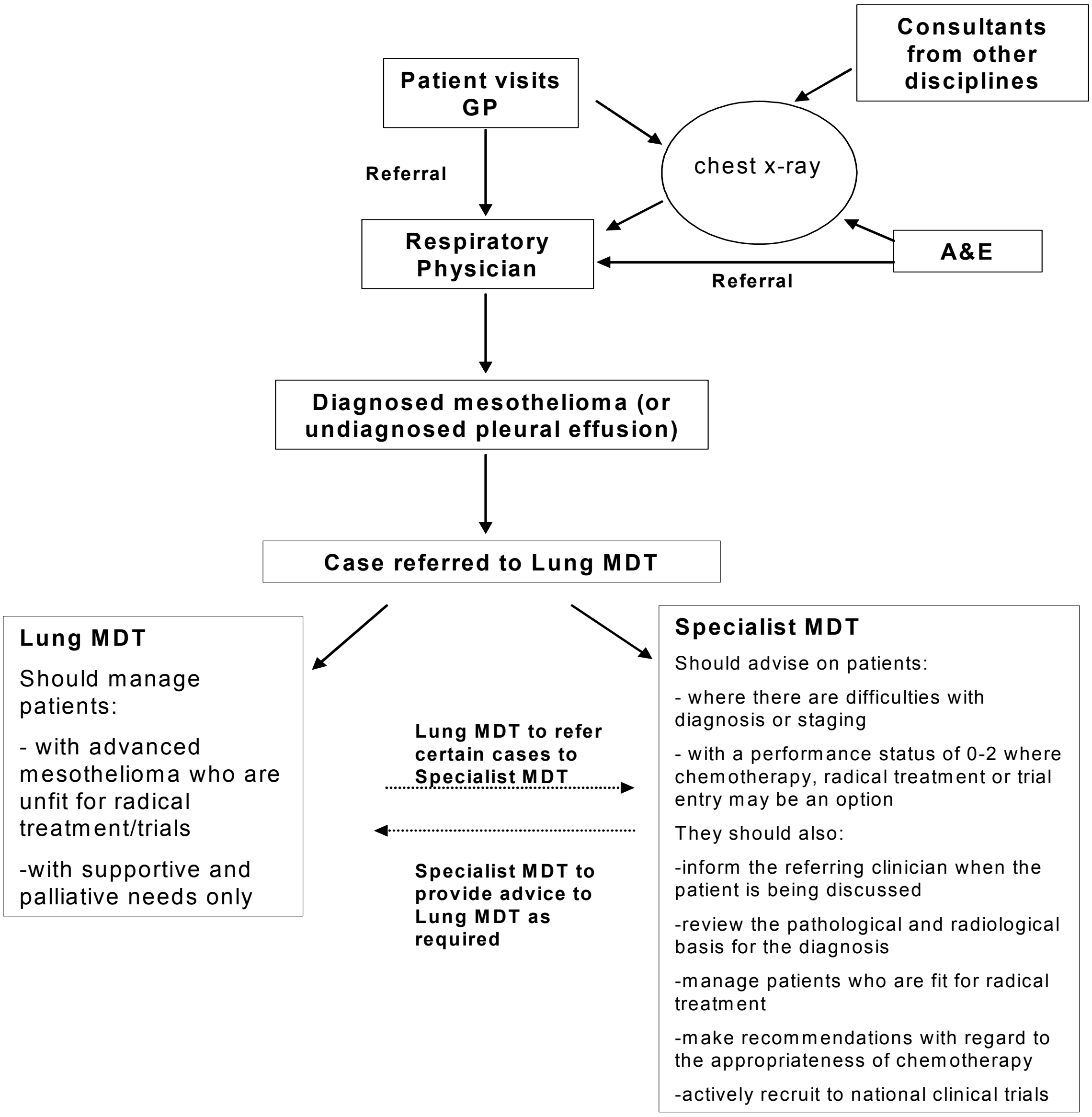
i. frequency of the specialist MDT meeting and attendance should be in line with lung MDT measures 2C-111 2C-112/2C-113 in the Manual for Cancer Services ie. meetings held at least fortnightly and members (or their arranged "cover") to attend at least half of the meetings initially moving to attending at least two thirds of meetings when feasible.

j. the designated specialist MDTs should have access to the lung cancer MDT extended team as set out in the Manual for Cancer Services (Measure 2C-130). In addition they may need access to a physiotherapist, occupational therapist or dietician.

The recommendations in this section are consistent with service reconfigurations taking place for other cancers that require specialist care.

45. Implementation of these recommendations would result in the following patient pathway:

Typical Care Pathway following implementation of the mesothelioma framework



Lung MDT

Should manage patients:

- with advanced mesothelioma who are unfit for radical treatment/trials

-with supportive and palliative needs only

Specialist MDT

Should advise on patients:

- where there are difficulties with diagnosis or staging

- with a performance status of 0-2 where chemotherapy, radical treatment or trial entry may be an option

They should also:

-inform the referring clinician when the patient is being discussed

-review the pathological and radiological basis for the diagnosis

-manage patients who are fit for radical treatment

-make recommendations with regard to the appropriateness of chemotherapy

-actively recruit to national clinical trials

Raising Awareness

46. As with all cancers, it is likely that the earlier mesothelioma is diagnosed the better the outcome for the patient in terms of improved symptom control and possibly length of survival. To ensure early presentation, the awareness of mesothelioma among two target audiences needs consideration:

    a. the public;
    b. clinicians (both in primary care and non-specialist hospital departments).

Public

47. There is very little known about public awareness of this condition and whether/if there is benefit to be gained by raising awareness of the risk across the general population given the potential psychologicial impact of knowing that, even if you were diagnosed early, mesothelioma is at present an incurable disease.

48. The general consensus from the consultation was that raising public awareness was not appropriate for inclusion in this framework. However, it was acknowledged that there may be a role for the voluntary sector, unions and trade associations to do this, for example, targeting messages in DIY stores and trade magazines.

Clinicians

49. GPs have a critical role in assessing any patients who present with symptoms that could be due to cancer. They need to be able to decide appropriately which patients can be reassured, which should be observed within primary care, which require routine investigations and which require urgent assessment by a specialist. NICE issued "*Referral guidelines for suspected cancer*" in June 2005 to help primary care staff identify those patients who are most likely to have cancer and who therefore require urgent assessment by a specialist. The guideline did not address mesothelioma although it did include a section on lung cancer (see ***Annex A***). The presenting symptoms suggestive of lung cancer and mesothelioma are broadly the same.

50. If primary care professionals follow the NICE referral guidelines for lung cancer then it is more likely that mesothelioma patients will be referred to a specialist in a timely manner. However, it should be noted that an individual GP is likely to see at least several hundred patients with these signs or symptoms each year but could go several years without ever having a single patient diagnosed with mesothelioma. It is therefore unlikely that a national initiative to raise awareness of mesothelioma amongst primary care staff would be desirable or feasible.

51. Many patients with pleural effusion (a build-up of fluid between the layers of the lining in the chest) come to hospital under the care of clinicians other than respiratory physicians or thoracic surgeons. Experience has shown that where these patients go on to have a diagnosis of mesothelioma, that diagnosis can be delayed and that they are not always referred to a specialist team. Therefore efforts need to be made to increase awareness and encourage early referral amongst non-specialist hospital clinicians. This may be best done using the expertise of the network mesothelioma clinical leads. Local promotion of a protocol for the referral and management of pleural effusions is a key element of such a process.

Recommendations

52. It is recommended that:

    a. PCTs in areas associated with asbestos-related industries/high mesothelioma incidence consider targeted local initiatives in primary care (and perhaps local hospitals) to:

        i. maintain among local clinicians a higher level of suspicion of the disease in appropriate patients than may be necessary in other parts of the country For example, PCTs could:

            - remind their GPs/practice nurses of those patients where they should have a high index of suspicion ie. males over 50 with:

                - a history of asbestos exposure or employment in high risk industries or those with possible ‘casual’ exposure such as the building industry;
                - a suspicious chest x-ray eg. showing unexplained pleural effusion or thickening; and/or
                - the following clinical features: pleural effusion; unexplained chest pain; breathlessness & weight loss.

            - Advise GPs to urgently refer patients with a history of employment in high risk industries – including those with ‘casual’ exposure such as the building industry - for a chest x-ray if they have pleural effusion, unexplained chest pain, breathlessness or weight loss.

            - advise their GPs to have a low threshold for requesting a repeat chest x-ray (2-3 months after a negative x-ray) if symptoms persist and employment history is high risk.

            - ask that primary care staff explore and document possible occupational risks or potential asbestos exposure in patients with suggestive respiratory symptoms.

  - record on patient records (in primary and secondary care) occupational history and where asbestos exposure is definite or likely.

b. ensure all local clinicians know what to do if they have a suspicion of mesothelioma ie. when and where to refer patients for specialist advice.

Clinical management

53. There is insufficient high level evidence for NICE to be asked to produce a clinical guideline on the management of mesothelioma.

54. This framework is aimed at service configuration rather than the clinical diagnosis and management of mesothelioma. It does not therefore include detail about how to diagnose or treat mesothelioma – this will be addressed in the updated British Thoracic Society statement on malignant mesothelioma due to be published later this year.

55. There are however, a number of organisational issues related to diagnosis, clinical management, supportive& palliative care and the role of clinical nurse specialists where there is a high level of professional consensus. These are outlined in the following sections.

Diagnosis

56. Mesothelioma patients can present with symptoms such as breathlessness, chest pain, weight loss, sweating and fatigue which may be non-specific. It may not always be immediately apparent that the patient has a history of exposure to asbestos. It is not uncommon for patients to undergo multiple procedures before a diagnosis is made or for there to be delays in diagnosis as patients are referred between specialties for assessment. For some patients the definitive diagnosis of mesothelioma will not be made until after death when an autopsy examination is performed.

57. Both pathological and radiological diagnosis of mesothelioma can be difficult. For example:

    a. cytology of pleural effusions or histopathological examination of tissue specimens is not straightforward, as the appearances may mimic those of a wide range of other malignancies including sarcoma. However there have been advances in laboratory techniques including immunohistochemistry which now enables the diagnosis to be made with more confidence. This will be covered in the British Thoracic Society Statement on Mesothelioma;

    b. interpretation of imaging investigations (especially contrast-enhanced CT scans of the thorax) require a high level of expertise;

    c. image-guided biopsy of the pleura using CT or ultrasound guided biopsy or thoracoscopy (medical or surgical) have a much higher diagnostic rate than blind pleural biopsy but the latter is still frequently used.

    The diagnosis of mesothelioma can therefore often be difficult and yet accurate diagnosis is essential for the quality control of clinical management and to underpin any claims for compensation. The updated BTS statement should help with this.

Recommendations:

58. To ensure that a diagnosis of mesothelioma can be made as early as possible, it is recommended that:

    a. Rapid access lung cancer clinics, as recommended in the NICE clinical guideline on lung cancer, also accept referrals of suspected mesothelioma cases.

    b. Networks ensure that all lung MDTs have access to image-guided percutaneous pleural biopsy including CT (or ultrasound) guided biopsy and medical or surgical thoracoscopy.

c. The British Thoracic Society (BTS) in collaboration with the Royal College of GPs (RCGP), Royal College of Radiologists (RCR) and the Royal College of Pathologists (RCPath) develop national guidelines on the management of pleural effusions - many patients present with a pleural effusion (of which mesothelioma is one cause amongst many) and yet, according to the questionnaire referred to in para 31, only 50% of networks had a protocol for the management of this condition.

d. The pathologist in the specialist MDT should ideally review the biopsies of all cases discussed, (especially those considered for radical surgery) and provide guidance and assistance for other pathologists in the Network as appropriate. The pathologist in the specialist MDT should have access to a national pathology reference panel for particularly difficult cases.

e. The Royal College of Pathologists should develop national guidelines for the appropriate laboratory tests needed to make a diagnosis of mesothelioma. These guidelines should be regularly reviewed to accommodate advances in diagnostic techniques.

Treatment

59. Less than 40% of mesothelioma patients may be fit for radical treatment by the time of diagnosis. At present there is no consensus on the optimum form of management for patients with mesothelioma - there is uncertainty about how it should be treated and no treatment has been unequivocally shown to have more than a modest impact on survival. However, it is expected that the updated British Thoracic Society statement on malignant mesothelioma, due to be published later this year, will provide some helpful advice for clinicians diagnosing and managing this condition.

Recommendations

60. It is recommended that:

    a. the lung MDTs, in association with their specialist MDT where appropriate, consider treatment and care options, including psychosocial needs, for all mesothelioma patients before a treatment/care plan is discussed and agreed with the patient;

    b. wherever possible and appropriate, entry into clinical trials is explored with patients;

    c. discussions are held at network level with local oncologists as to the most appropriate location(s) at which chemotherapy should be administered. Patient choice should be taken into account when individual treatment options are being considered.

Supportive and Palliative Care

61. As mesothelioma is almost always fatal, all patients will need palliative interventions and care at different stages of their illness. Supportive and palliative care therefore has a key role to play for both patients and their families and carers.

62. Patients with mesothelioma frequently suffer distressing symptoms. These may include breathlessness, chest pain, fatigue and weight loss. Intractable pain in particular is a key issue. Specialist palliative care including specific interventions such as radiotherapy to the site of chest drainage/biopsy, nerve blocks & cordotomy, are of particular importance in providing relief for some patients.

63. Implementation of the NICE guidance on "*Improving Supportive & Palliative Care for Adults with Cancer"* should ensure that patients receive optimal symptom control together with psychological, social and spiritual care throughout the course of their illness.

Recommendations

64. It is recommended that:

    a. the NICE guidance on "*Improving Supportive & Palliative Care for Adults with Cancer"* should be implemented across networks as soon as possible.

    b. whilst the NICE guidance is being implemented:

        i. referral pathways between lung MDTs and specialist palliative care teams or pain management teams (if different) should be clear;
        ii. every patient with mesothelioma should be reviewed by a clinical nurse specialist who would usually act as their 'key worker' during the course of their illness (see para 66d).
        iii. palliative care and symptom control should be central to any management plan for mesothelioma patients.

Clinical Nurse Specialists

65. The support of Clinical Nurse Specialists (CNS) is a vital part of the cancer care pathway. Nurse specialists have established themselves across all tumour sites and are considered pivotal to:

    a. meeting the psychological, social and spiritual needs of patients;

    b. streamlined, responsive care pathways which are able to meet the individual needs of patients and their family / carers;

    c. the provision of information within a supportive environment (see para 71b);

    d. the flow of communication to patients and across all members of the health care team.

    CNSs need not necessarily perform all these functions themselves but it is their responsibility to make sure these tasks are undertaken. Some CNSs may take on more strategic roles including, data collection and education.

Recommendations

66. It is recommended that:

    a. CNSs (usually the lung cancer nurse specialist) within each Lung MDT be responsible for providing support and information for mesothelioma patients and their families as well as lung cancer patients unless the workload is such that a dedicated mesothelioma CNS is required locally.

    b. The CNS assesses the patient throughout their care pathway to identify:

        i. symptom control needs;
        ii. psychological needs including hopes and fears for the future;
        iii. social needs including the availability of family/carer support; ability to cope, appropriateness of current housing, needs of (and provision for) dependents, occupational history and exposure to asbestos, ability and need to work;
        iv. spiritual needs including religious preferences & need and end of life issues;
        v. information needs (see para 71).

    c. the CNS within the specialist MDT should be able to provide advice and support to CNSs in associated lung MDTs (ie. the lung MDTs that can refer to that specialist MDT) and ensure that clear arrangements are in place should it be necessary to transfer the care of a patient between the two teams.

d. all mesothelioma patients have a key worker – this is likely to be the lung CNS initially who should be able to facilitate referrals/contact with members of the extended MDT (see para 44j) as required until such time as it is agreed that a member of the palliative care team should take over this role.

e. the CNS in the lung MDT works with the CNS in the specialist MDT to develop a streamlined, responsive care pathway that is able to meet the needs of individual patients. This would require:-

    i. the establishing of good communication channels within and between the MDTs, GP, primary care nursing teams, the patient and their family;
    ii. access for the patient to members of the care team via the keyworker;
    iii. simple referral processes for other members of the health care team (incl. palliative care, physiotherapy, hospital chaplain, occupational therapist, social worker, psychologist) to ensure that referrals occur as the need arises and at a time that is appropriate to the individual patient;
    iv. comprehensive, accurate and accessible nursing documentation.

f. patient preference and choice is considered at different stages of the patient journey (supported by accurate information) and fed back to the appropriate MDT.

Underpinning Programmes

Communication, information and support

67. Communication, information and support for cancer patients is addressed in the guidance issued by the National Institute for Health & Clinical Excellence (NICE) on "*Improving Supportive & Palliative Care for Adults with Cancer*" in March 2004. When this guidance is fully implemented across the NHS this will greatly benefit all cancer patients including those with mesothelioma ensuring that they receive information in a timely manner and at appropriate stages.

68. Mesothelioma is, in most cases, an industrial disease and therefore, in addition to the measures set out in the NICE guidance there is a need for high quality and timely information for both patients and carers about medico-legal and benefit-related issues. In their report on asbestos related diseases the Industrial Injuries Advisory Council (IIAC) recognised that a proportion of mesothelioma patients who are eligible for industrial injury benefit do not claim it. They believed that one important reason for this may be a lack of awareness of the Scheme. They recommended that the provisions of the IIDB Scheme be highlighted to mesothelioma patients.

69. In addition, some NHS staff may not be aware that it is not always necessary for a mesothelioma patient to have a definitive diagnosis of mesothelioma in order to receive some occupational related benefits eg. industrial injuries disablement benefit.

70. There are already a number of sources of information on mesothelioma including several charities and support groups such as:

    a. Mesothelioma UK (the National Macmillan Mesothelioma Resource Centre);
    b. British Lung Foundation;
    c. Cancerbackup;
    d. Cancer Research UK;
    e. Many local asbestos support groups.

Recommendations

71. It is recommended that:

    a. Cancer networks implement recommendations on information, communication and support in the NICE guidance on Improving Supportive & Palliative Care for Adults with Cancer as soon as possible.

    b. Clinical Nurse Specialists are responsible for the provision of information in a timely manner and within a supportive environment and ensuring that a patient's level of understanding is assessed, documented and communicated throughout the care pathway (see para 66).

c. Network wide information, rather than unit specific information, is developed for mesothelioma where possible.

d. Mesothelioma patients know how to access information on benefits and legal advice on possible compensation – to support this the CNS should signpost patients to websites, telephone helplines, support groups and local information services as appropriate, for example, to Asbestos Support Groups, Cancer Information Centres, Citizens Advice Bureaus and benefits and legal advisors (see ***Annex B***).

e. Each CNS should have available a Mesothelioma Patient Information Pack that should include as a minimum information about:

   i. the disease;
   ii. local NHS services and care/treatment options;
   iii. possible benefits and compensation (see ***Annex B***)
   iv. where to go for further advice/support including out of hours NHS support.

   CNS will need to determine when it is most appropriate to give information from this pack to patients.

Mesothelioma research/clinical trials

72. Research can lead to improved quality of care for patients. Research funding for mesothelioma-related studies has been limited in the past and research spend in this area is low in comparison to some other cancer types. Research is vital if advances are to be made in the diagnosis and treatment of this disease and more international trials may need to be considered in order to recruit higher numbers of patients.

73. The 2000 NHS Plan announced that the Department of Health would provide an additional £20 million per year to establish a national cancer research network. The National Cancer Research Network (NCRN) and the National Translational Cancer Research Network (NTCRN) were established as a result. As at February 2007, the NHS is currently supporting three mesothelioma studies through the NCRN. These are:

    a. the ***MALCS study*** (funded by the Health and Safety Executive) – a population based case-control study of mesothelioma and lung cancer in relation to occupation in British men and women under the age of 60. The study looks at the occupations of men and women and the possible link this has with the development of lung cancer and mesothelioma;

    b. the ***MARS (Mesothelioma and Radical Surgery) study*** (funded by Cancer Research UK and the June Hancock Mesothelioma Research Fund). This is a pilot study to determine the feasibility and acceptability of performing a randomised trial comparing extra-pleural pneumonectomy (EPP) against no EPP surgery within the context of trimodality therapy (chemotherapy, surgery, post-operative radiotherapy). It is currently recruiting ahead of schedule;

    c. the ***MESO-VATS study*** (funded by the BUPA foundation) – a prospective randomised controlled trial of video-assisted thoracoscopic (VATS) cytoreductive pleurectomy compared to talc pleurodesis in patients with suspected or proven malignant mesothelioma. This has been underway for 2 years and is expected to expand into further centres.

74. The ***MES01 trial*** - a trial which compared chemotherapy against active supportive care alone for patients with malignant pleural mesothelioma recently closed for recruitment. It is expected to report in 2007 and planning is underway for MES02.

75. The National Cancer Research Institute (NCRI) Lung Clinical Studies Group has established a mesothelioma sub-group to facilitate the development of these and other clinical trials in the disease. The sub-group will produce an annual report during 2007 setting out progress and developments.

Recommendations

76. It is recommended that:

    a. all appropriate mesothelioma patients should be offered the option of entering a clinical trial, where one relevant to their clinical condition is open for recruitment;

    b. the NCRI mesothelioma sub-group and other interested clinicians are encouraged to continue developing protocols for new clinical trials.

Audit and Patient Surveys

77. It is important to measure the quality of service being provided to enable MDTs to learn quickly from experience. To do this, teams need to ensure that they collect relevant information on patients' cases and carry out local audits.

78. The national lung cancer audit programme (LUCADA) is also designed for the collection of data on mesothelioma patients (a new version of the data collection system with more mesothelioma-specific data items is to be launched in the summer of 2007). MDTs managing/ treating mesothelioma patients should use this system to collect more detailed longitudinal data on this disease. If all MDTs collected this information via the LUCADA database it would be possible to have national data on:

    a. the incidence of new cases of mesothelioma by MDT and network;
    b. the proportion of patients with a pathological diagnosis;
    c. the proportion of patients receiving surgery, radiotherapy, chemotherapy and specialist palliative care;
    d. the proportion of patients entered into a clinical trial
    e. the survival of mesothelioma patients by MDT and network;
    f. deaths related to treatment.

79. It should be noted that patient experience is also key to assessing the quality of a service and patient surveys are a key vehicle to assess this.

Recommendations

80. It is recommended that:

    a. all MDTs that manage mesothelioma patients participate in the National Lung Cancer Audit Programme (LUCADA).

       [Information is available via the NHS Health and Social Care Information Centre website, the url address is: http://www.icservices.nhs.uk/ncasp/pages/audit_topics/lungcancer/default.asp?om=m1.

    b. all network/trusts ensure that their regular surveys of patient experiences include mesothelioma patients

Conclusion

81. A peak in mortality is less than 10 years away so there is a real opportunity to ensure that the NHS has done all it can to provide a high quality service for the increasing number of patients that will be diagnosed with mesothelioma over the next few years.

82. The recommendations set out in this framework are summarised at para 82 and the NHS is advised to:

    a. discuss the recommendations at a clinical and organisational level; and,

    b. take them into account as it develops, provides and commissions services for mesothelioma patients.

Summary of Recommendations

83. This framework recommends that:

Cancer Networks

a. Each cancer network should have a lead clinician and lead nurse for mesothelioma.

b. Each lead clinician/nurse should have an agreed list of responsibilities (in line with the role set out at para 38c). They should also have time set out in their job description (for the clinician, expressed in whatever units are used in their contract) to carry out those responsibilities. The time needed may differ between networks and administrative support may be needed.

c. The role of the network mesothelioma clinical and nursing leads should be:

    i. to benchmark clinical activity for the past year, for example bringing together data on the incidence of mesothelioma in their network and the numbers of patients being discussed at each of their MDTs, in order to establish the baseline position locally and to monitor trends and changes in practice;
    ii. to carry out a mesothelioma needs assessment for their local population, if one has not been done in the last 12 months, to identify the nature of any problems and how they might be resolved (this would include the availability of the relevant clinical expertise within their network);
    iii. to assist/support the implementation of this framework, for example by:

        - ensuring specialist MDTs are in place in line with paras 44c-j;
        - ensuring, in consultation with the lung cancer network site specific group, that referral pathways are clear & relevant protocols developed that can take into account the circumstances and preferences of individual patients;
        - supporting cross network co-ordination/ communication including ensuring that efficient arrangements are in place for the timely transfer of notes, images and pathological specimens between MDTs;
        - ensuring that details of relevant clinical trials are available to their MDTs;
        - ensuring that lung MDTs submit data on all mesothelioma cases to the National Lung Cancer Audit Programme (LUCADA) - see para 80;
        - ensuring (even once the framework is implemented), that local population needs are regularly reviewed and that

    there is on-going audit and feedback to the network about the quality of services provided;
  - acting as a mesothelioma 'resource' for the local area including a role in encouraging colleagues in MDTs to undertake appropriate education and training.

iv. to contribute to the recently established network of mesothelioma leads which seeks to share experiences and good practice with the aim of improving services for this group of patients nationally.

Multi-disciplinary Teams (MDTs)

d. all patients with diagnosed mesothelioma or an undiagnosed unilateral pleural effusion, where mesothelioma is a possible diagnosis, should have their case discussed by a lung cancer MDT.

e. lung MDTs should confirm the diagnosis of mesothelioma where possible, based on radiological images and pathology reports available at the meeting, and manage patients with advanced mesothelioma who are unfit for radical treatment/ trials or who have palliative and supportive care needs only.

f. a number of existing lung MDTs should be designated as specialist MDTs to advise on the diagnosis of more difficult mesothelioma cases and, in some cases, the management of patients.

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   ii. patients with a performance status (PS) of 0-2 (estimated at around 43% of mesothelioma patients) where chemotherapy, radical treatment including surgery or multimodality therapy, or trial entry may be an option;

h. the specialist MDT should:

   i. inform the referring clinician when the patient is being discussed at the Specialist MDT and invite them to attend the meeting if they so wish;
   ii. review the pathological and radiological basis for the diagnosis, particularly in all patients where radical treatment is being considered;
   iii. manage patients who are fit for radical surgical or multi-modality treatment (patients considered possible candidates for extrapleural pneumonectomy or radical debulking surgery may need to be referred onwards to one of the other specialist MDTs if they don't have the appropriate surgical expertise);

   - iv. make recommendations with regard to the appropriateness of chemotherapy although the location of chemotherapy administration should be agreed locally within the network;
   - v. actively encourage the recruitment of appropriate patients to relevant national clinical trials.

i. designation of certain lung MDTs as specialist MDTs should be for local determination following a review of the mesothelioma caseload and discussion with stakeholders including the cancer network and local specialist commissioning group. These MDTs need not necessarily be based at university or teaching hospitals. A district general hospital could equally well host a specialist MDT if that is where the necessary expertise is located. It is however expected that most specialist MDTs will be based around centres with thoracic surgical services or where there are visiting surgeons with expertise in this area.

j. a specialist MDT would need a reasonable throughput of cases in order to develop and maintain expertise - a minimum of 25 mesothelioma cases a year is suggested. The survey results (see para 32), indicate that an annual caseload of 25 is likely to enable the designation of one specialist MDT in most networks.

k. where the caseload is not sufficient to support a specialist MDT within the boundaries of a network a protocol to support referrals to another network's specialist MDT should be put in place.

l. the membership of the designated specialist MDT would be the same as that for the lung MDT. However, the respiratory physician, thoracic surgeon, oncologist, clinical nurse specialist, imaging specialist, pathologist and member of the palliative care team would need to have, or develop, a specialist interest in mesothelioma.

m. frequency of the specialist MDT meeting and attendance should be in line with lung MDT measures 2C-111 2C-112/2C-113 in the Manual for Cancer Services ie. meetings held at least fortnightly and members (or their arranged "cover") to attend at least half of the meetings initially moving to attending at least two thirds of meetings when feasible.

n. the designated specialist MDTs should have access to the lung cancer MDT extended team as set out in the Manual for Cancer Services (Measure 2C-130). In addition they may need access to a physiotherapist, occupational therapist or dietician.

Raising Awareness in Clinicians

o. PCTs in areas associated with asbestos-related industries/high mesothelioma incidence consider targeted local initiatives in primary care (and perhaps local hospitals) to:

i. maintain among local clinicians a higher level of suspicion of the disease in appropriate patients than may be necessary in other parts of the country For example, PCTs could:

    - remind their GPs/practice nurses of those patients where they should have a high index of suspicion ie. males over 50 with:

        - a history of asbestos exposure or employment in high risk industries or those with possible ‘casual’ exposure such as the building industry;
        - a suspicious chest x-ray eg. showing unexplained pleural effusion or thickening; and/or
        - the following clinical features: pleural effusion; unexplained chest pain; breathlessness and weight loss.

    - advise GPs to urgently refer patients with a history of employment in high risk industries – including those with ‘casual’ exposure such as the building industry - for a chest x-ray if they have pleural effusion, unexplained chest pain, breathlessness or weight loss.

    - advise their GPs to have a low threshold for requesting a repeat chest x-ray (2-3 months after a negative x-ray) if symptoms persist and employment history is high risk.

    - ask that primary care staff explore and document possible occupational risks or potential asbestos exposure in patients with suggestive respiratory symptoms.

    - record on patient records (in primary and secondary care) occupational history and where asbestos exposure is definite or likely.

ii. ensure all local clinicians know what to do if they have a suspicion of mesothelioma ie. when and where to refer patients for specialist advice.

Diagnosis

p. Rapid access lung cancer clinics, as recommended in the NICE clinical guideline on lung cancer, also accept referrals of suspected mesothelioma cases.

q. Networks ensure that all lung MDTs have access to image-guided percutaneous pleural biopsy including CT (or ultrasound) guided biopsy and medical or surgical thoracoscopy.

r. The British Thoracic Society (BTS) in collaboration with the Royal College of GPs (RCGP), Royal College of Radiologists (RCR) and the Royal College of Pathologists (RCPath) develop national guidelines on the management of pleural effusions - many patients present with a pleural effusion (of which mesothelioma is one cause amongst many) and yet, according to the questionnaire referred to in para 31, only 50% of networks had a protocol for the management of this condition.

s. The pathologist in the specialist MDT should ideally review the biopsies of all cases discussed, (especially those considered for radical surgery) and provide guidance and assistance for other pathologists in the Network as appropriate. The pathologist in the specialist MDT should have access to a national pathology reference panel for particularly difficult cases.

t. The Royal College of Pathologists should develop national guidelines for the appropriate laboratory tests needed to make a diagnosis of mesothelioma. These guidelines should be regularly reviewed to accommodate advances in diagnostic techniques.

Treatment

u. the lung MDTs, in association with their specialist MDT where appropriate, consider treatment and care options, including psychosocial needs, for all mesothelioma patients before a treatment/care plan is discussed and agreed with the patient.

v. wherever possible and appropriate, entry into clinical trials is explored with patients.

w. discussions are held at network level with local oncologists as to the most appropriate location(s) at which chemotherapy should be administered. Patient choice should be taken into account when individual treatment options are being considered.

Supportive and Palliative Care

x. the NICE guidance on "*Improving Supportive & Palliative Care for Adults with Cancer"* should be implemented across networks as soon as possible.

y. whilst the NICE guidance is being implemented:

   i. referral pathways between lung MDTs and specialist palliative care teams or pain management teams (if different) should be clear;
   ii. every patient with mesothelioma should be reviewed by a clinical nurse specialist who would usually act as their 'key worker' during the course of their illness (see para 66d).

iii. palliative care and symptom control should be central to any management plan for mesothelioma patients.

Clinical Nurse Specialists

z. CNSs (usually the lung cancer nurse specialist) within each Lung MDT be responsible for providing support and information for mesothelioma patients and their families as well as lung cancer patients unless the workload is such that a dedicated mesothelioma CNS is required locally.

aa. The CNS assesses the patient throughout their care pathway to identify:

  i. symptom control needs;
  ii. psychological needs including hopes and fears for the future;
  iii. social needs including the availability of family/carer support; ability to cope, appropriateness of current housing, needs of (and provision for) dependents, occupational history and exposure to asbestos, ability and need to work;
  iv. spiritual needs including religious preferences & need and end of life issues;
  v. information needs (see para 71).

bb. the CNS within the specialist MDT should be able to provide advice and support to CNSs in associated lung MDTs (ie. the lung MDTs that can refer to that specialist MDT) and ensure that clear arrangements are in place should it be necessary to transfer the care of a patient between the two teams.

cc. all mesothelioma patients have a key worker – this is likely to be the lung CNS initially who should be able to facilitate referrals/contact with members of the extended MDT (see 44j) as required until such time as it is agreed that a member of the palliative care team should take over this role.

dd. the CNS in the lung MDT works with the CNS in the specialist MDT to develop a streamlined, responsive care pathway that is able to meet the needs of individual patients. This would require:

  i. the establishing of good communication channels within and between the MDTs, GP, primary care nursing teams, the patient and their family;
  ii. access for the patient to members of the care team via the keyworker;
  iii. simple referral processes for other members of the health care team (incl. palliative care, physiotherapy, hospital chaplain, occupational therapist, social worker, psychologist) to ensure that referrals occur as the need arises and at a time that is appropriate to the individual patient;

    iv. comprehensive, accurate and accessible nursing documentation.

ee. patient preference and choice is considered at different stages of the patient journey (supported by accurate information) and fed back to the appropriate MDT.

Communication, information and support

ff. Cancer networks implement recommendations on information, communication and support in the NICE guidance on Improving Supportive & Palliative Care for Adults with Cancer as soon as possible.

gg. Clinical Nurse Specialists are responsible for the provision of information in a timely manner and within a supportive environment and ensuring that a patient’s level of understanding is assessed, documented and communicated throughout the care pathway (see para 66).

hh. Network wide information, rather than unit specific information, is developed for mesothelioma where possible.

ii. Mesothelioma patients know how to access information on benefits and legal advice on possible compensation – to support this the CNS should signpost patients to websites, telephone helplines, support groups and local information services as appropriate, for example, to Asbestos Support Groups, Cancer Information Centres, Citizens Advice Bureaus and benefits and legal advisors (see ***Annex B***).

jj. Each CNS should have available a Mesothelioma Patient Information Pack that should include as a minimum information about:

    i. the disease;
    ii. local NHS services and care/treatment options;
    iii. possible benefits and compensation (see ***Annex B***)
    iv. where to go for further advice/support including out of hours NHS support.

CNS will need to determine when it is most appropriate to give information from this pack to patients.

kk. There should be information/support for families across the care pathway including about what happens when a patient dies in terms of post mortem, coroner’s investigation/inquest etc.

Mesothelioma research/clinical trials

ll. all appropriate mesothelioma patients should be offered the option of entering a clinical trial, where one relevant to their clinical condition is open for recruitment.

mm. NCRI mesothelioma sub-group and other interested clinicians are encouraged to continue developing protocols for new clinical trials.

Audit and Patient Surveys

nn. all MDTs that manage mesothelioma patients participate in the National Lung Cancer Audit Programme (LUCADA).

oo. all network/trusts ensure that their regular surveys of patient experiences include mesothelioma patients

Annex A

NICE Guideline on Referral for Suspected Cancer
Extract on Lung cancer

General recommendations

1.3.1 A patient who presents with symptoms suggestive of lung cancer should be referred to a team specialising in the management of lung cancer, depending on local arrangements.

Specific recommendations

1.3.2 An urgent referral for a chest X-ray should be made when a patient presents with:

- haemoptysis, or
- any of the following unexplained persistent (that is, lasting more than 3 weeks) symptoms and signs:
    - chest and/or shoulder pain
    - dyspnoea
    - weight loss
    - chest signs
    - hoarseness
    - finger clubbing
    - cervical and/or supraclavicular lymphadenopathy
    - cough with or without any of the above
    - features suggestive of metastasis from a lung cancer (for example, in brain, bone, liver or skin).

A report should be made back to the referring primary healthcare professional within 5 days of referral.

1.3.3 An urgent referral should be made for either of the following:

- persistent haemoptysis in smokers or ex-smokers who are aged 40 years and older
- a chest X-ray suggestive of lung cancer (including pleural effusion and slowly resolving consolidation).

1.3.4 Immediate referral should be considered for the following:

- signs of superior vena caval obstruction (swelling of the face and/or neck with fixed elevation of jugular venous pressure)
- stridor.

Risk factors

1.3.5 Patients in the following categories have a higher risk of developing lung cancer:

- are current or ex-smokers
- have smoking-related chronic obstructive pulmonary disease (COPD)
- have been exposed to asbestos
- have had a previous history of cancer (especially head and neck).

An urgent referral for a chest X-ray or to a team specialising in the management of lung cancer should be made as for other patients (see 1.3.1 above) but may be considered sooner, for example if symptoms or signs have lasted for less than 3 weeks.

Investigations

1.3.6 Unexplained changes in existing symptoms in patients with underlying chronic respiratory problems should prompt an urgent referral for chest X-ray.

1.3.7 If the chest X-ray is normal, but there is a high suspicion of lung cancer, patients should be offered an urgent referral.

1.3.8 In individuals with a history of asbestos exposure and recent onset of chest pain, shortness of breath or unexplained systemic symptoms, lung cancer should be considered and a chest X-ray arranged. If this indicates a pleural effusion, pleural mass or any suspicious lung pathology, an urgent referral should be made.

Annex B

Help and Advice for People with Mesothelioma

1) People diagnosed with mesothelioma may be entitled to social security benefits and/or compensation from employers. This annex sets out:

   a) some of the benefits that patients/carers might be entitled to;
   b) compensation issues;
   c) organisations that might be able to provide information and advice about benefits and compensation to patients and their families.

Types of Benefit

Benefits related to employment

2) A patient (except if they were self-employed) may be entitled to the following benefits, if they have developed mesothelioma after coming into contact with asbestos as a result of paid employment:

   a) **Pneumoconiosis, Byssinosis and Miscellaneous Diseases Benefit Scheme** – a patient may be eligible to make a claim under this scheme if it is believed that the disease developed because of a job done before 5 July 1948;
   b) **Industrial Injuries Disablement Benefit (IIDB)** – a patient may be eligible for this benefit if the disease developed because of a job involving working with asbestos or being exposed to asbestos after 4 July 1948

   Claims for both these benefits should be made as soon as possible so that a patient does not lose out on benefits they may be entitled to. Patients, their families, or NHS staff can contact the Benefit Enquiry Line on 0800 88 22 00 if they need further information.

3) If exposure to asbestos might have happened during service in the armed forces rather than in other employment, a claim can be made for a ***war disablement pension*** from the Veterans Agency by contacting on 0800 169 2277.

Other Benefits

4) Other benefits that patients with mesothelioma or their carers may be eligible to claim (sometimes in addition to the benefits above) include:

   a) ***Disability Living Allowance*** – if someone is under the age of 65 they may be able to claim this allowance if they need help with personal care needs or have difficulty getting around because of their illness. If a patient's illness means that they are not expected to live for more than six months, special rules apply to claims for this allowance to make sure any entitlement is received quickly and easily.

b) ***Attendance Allowance*** – if someone is over the age of 65 and needs help with personal care needs because of their illness, they may be able to claim an Attendance Allowance. If a patient's illness means that they are not expected to live for more than six months, special rules apply to claims for this allowance to make sure any entitlement is received quickly and easily.

c) ***Constant Attendance Allowance*** – if a patient is in receipt of Industrial Injuries Disablement Benefit or a War Disablement Pension and needs daily care and attention because of the disability they may also be entitled to claim a Constant Attendance Allowance.

d) ***Carer's allowance*** – if a patient is in receipt of the highest or middle rate care component of Disability Living Allowance, Attendance Allowance or some rates of Constant Attendance Allowance and has someone helping to look after them, they may also be entitled to claim a Carer's Allowance.

e) Other benefits may also be paid to replace or top up earnings and help with housing costs - it is important that patients get expert advice about all these benefits and the Benefit Enquiry Line on 0800 88 22 00 is a useful starting point.

Compensation

5) If mesothelioma is likely to have been caused by exposure to asbestos at work, it may be possible to claim compensation from the employer, or from several employers, by suing them for negligence. If mesothelioma is likely to have been caused because of clothing contamination or environmental exposure, it may also be possible to claim compensation from the relevant firm.

6) This is a very specialised area of law and a patient or their family should seek advice from a specialist solicitor who will know how to deal with a claim and to make sure it is dealt with as quickly as possible. If the person with mesothelioma is a union member, or was when they worked with asbestos, their union may be able to refer them to an experienced solicitor. If not, a local Asbestos Victims Support Group if one exists in the area, will be able to help with advice. They will know of expert solicitors. The Association of Personal Injury Lawyers also has a list of experienced asbestos solicitors and the Law Society, or the Law Society of Scotland, will be able to provide a patient with a list of solicitors in their area.

7) As exposure may have happened several decades ago, an employer may no longer be in business. This does not mean that a claim cannot be made, as the solicitor may be able to claim against the employer's

insurer. In addition, **the Pneumoconiosis Etc. (Workers' Compensation) Act 1979 (1979 Act)** provides one-off lump sum compensation for sufferers (or their dependants if they have died) of this disease who are unable to claim damages from the employers who caused the disease, because they have ceased trading.

Sources of help, advice and support

8) Leaflets are available for some of the benefits referred to in this annex setting out more information about the qualifying conditions, how to claim and where to obtain the relevant claim forms. These can be downloaded and printed from: http://www.jobcentreplus.gov.uk/jcp/customers/leaflets_and_guides/dev_011720.xml.html.

9) In addition, the following are useful sources of advice for patients with, or families affected by, mesothelioma along with NHS employees who may require advice:

   a) Mesothelioma UK (the National Macmillan Mesothelioma Resource Centre): 0800 169 2409
   b) Cancer BACUP: 0808 800 1234
   c) British Lung Foundation helpline: 0845 850 5020
   d) Department for Work and Pensions benefit enquiry line 0800 88 22 00, Textphone 0800 24 33 55
   e) Forum of Asbestos Victims Support Groups: 0161 636 7555
   f) Association of Personal Injury Lawyers: 0870 609 1958
   g) Law Society: 0870 606 6575
   h) The Law Society of Scotland: 0131 226 7441
   i) Local Citizens Advice Bureau, Veterans Agency, Welfare Rights Organisations and Trade Unions can be found in the phone book.
   j) Veterans Agency 0800 169 2277, Textphone 0800 169 3458
   k) Benefit Enquiry Line: Phone: 0800 88 22 00Textphone: 0800 24 33 55
   l) http://www.direct.gov.uk/disabledpeople

DH INFORMATION READER BOX

[✓ **Policy**]
HR / Workforce
Management
Planning
Clinical
Estates
Performance
IM & T
Finance
Partnership Working

Document Purpose	Best Practice Guidance
ROCR Ref:	
Gateway Ref:	7907
Title	Mesothelioma Framework
Author	Department of Health, Clinical Programmes: Cancer
Publication Date	27 Feb 2007
Target Audience	Network Mesothelioma Leads, Network Lead Clinicians, Network Lead Managers, SHA Cancer Leads
Circulation List	PCT CEs, NHS Trust CEs, SHA CEs, Medical Directors, Local Authority CEs
Description	This Framework aims to provide Strategic Health Authorities, Cancer Networks, Primary Care Trusts and NHS Trusts with advice on how to organise services for mesothelioma patients to improve quality of care across the country.
Cross Ref	N/A
Superseded Docs	The Draft Mesothelioma Framework (consultation document)
Action Required	N/A
Timing	**N/A**
Contact Details	Cheryl Cavanagh Department of Health 133-155 Waterloo Road London SE1 8UG 0207 972 1312
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